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ABSTRACT

The handbook presents exercises to help parents of handicapped children become more assertive in securing services for their children. An introductory section explains the basic premises of the handbook: (1) that parents are equal partners with professionals; (2) that parents are the authority on their child; and (3) that parents have 10 specific rights, including rights to question decisions regarding their child and to make mistakes without feeling guilty. Assertive and nonassertive behaviors are contrasted. A second section is devoted to developing positive attitudes while eliminating negative ones, and contains chapters with titles such as "How to Get Rid of the Shakes and Put Punch in Your Speeches" and "How to Put Down the Put Down." The third section, on assertiveness at special education meetings, discusses the parents' role in individualized education program meetings and due process hearings. Assertiveness exercises follow which focus on dealing with the bureaucracy through such techniques as repetition and escalation. A section on assertiveness with bureaucrats and public officials includes suggestions for public hearings and use of the media. A final section presents accounts of parents and family members who achieved success through assertive behavior. (CL)

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FOR PARENTS
OF
HANDICAPPED CHILDREN
AND THEIR HELPERS

HOW TO Get Services by Being ASSERTIVE

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How To Get Services By Being Assertive

BY

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WHO WE ARE - WHAT WE DO

NATIONAL PARENT ORGANIZATIONS

OTHER IMPORTANT ORGANIZATIONS

OTHER CCHC PUBLICATIONS

INTRODUCTION

The contents of this handbook are based on thousands of calls, letters and personal contacts with parents of handicapped children during The Coordinating Council's ten-year existence. During that time, thousands of parents have complained to The Coordinating Council for Handicapped Children about:

1. lack of services
2. denial of services
3. intimidation tactics by bureaucrats
4. inaccessibility of bureaucrats
5. lack of response to legitimate demands
6. red tape and other bureaucratic obstacles to service

The assertiveness training exercises and other techniques described in this book were developed - and used successfully by The Coordinating Council in direct response to these parent complaints. Since most of these phone, letter and personal contacts have been made by female parents, female pronouns are used in this book.

Let us know of your success or failure - in using these techniques, and we will incorporate your responses in our next edition of HOW TO GET SERVICES BY BEING ASSERTIVE

PART I

ASSERTIVE

VS.

NON-ASSERTIVE —

WHICH ARE YOU?

1
Why This Handbook?

Why do parents and professionals need a handbook called HOW TO GET SERVICES BY BEING ASSERTIVE? The answer is: Many parents are not receiving the services they are entitled to by law for their handicapped child; and, many professionals have been unable to obtain services their parent/consumer clients are legally entitled to.

THIS HANDBOOK IS WRITTEN IN DIRECT RESPONSE TO THE MANY PARENTS - and professionals - who have expressed to the Coordinating Council for Handicapped Children their feelings of frustration and impotence at their inability to get services.

Why are parents and professionals unable to get services? Why are the needs of handicapped children often the last priority of local, state and federal agencies?

WE OFFER THE FOLLOWING REASONS:

1. Entrenched bureaucracies that are often paralysed in their status-quo way of doing things.

2. Lack of enough money to meet ALL the demands of EVERYONE

3. Other priorities for the limited amount of funds available (the money goes to others who are more assertive)

4. Low expectations of parents and professionals - which are conveyed in their non-assertive approaches. Parents and professionals often convey the message by their non-assertiveness, by their resignation to the status quo and lack of services, that they really don't expect very much. RESULTS? They get exactly what they expect. Little or nothing! After all, why should a bureaucrat go out of his way to provide a service; why should he stick his neck out and demand more money and more services for handicapped children - if he's not really expected to? Why should anyone?

WHY ARE PARENTS NON ASSERTIVE? Because parents have been taught intimidation throughout their many years of communication with bureaucrats who tell them: "We know what's best for your child. We're experts, and you're only a parent..."

The "I'm Only a Parent Syndrome" becomes evident early in the life of a parent of a handicapped child. From her first contact with the professionals who diagnosed her child; to the school officials who tell her what they will or will

not do for her child; to the bureaucrats who tell her "No, we just don't have the money to give you what you want..." the parent soon begins to identify herself, at first, only to herself - but eventually to others as well - as "only a parent".

She wears her "I'm only a parent" tag to meetings with school officials, and she gets the "You're only a parent" treatment from them. At public meetings, conferences, workshops, seminars, she identifies herself as "I'm only a parent", and the professionals present usually agree.

PROFESSIONALS, TOO, ARE INTIMIDATED - in different ways, and for different reasons. And, as a result, they, too, are afraid to be assertive. They are afraid they will:

1. become known as "trouble-makers" by their superiors and get poor ratings as a result

2. be passed over for a promotion

3. lose their jobs and get poor recommendations.

4. put their "professional" careers in jeopardy

THIS HANDBOOK IS DEDICATED TO THE PREMISE THAT PARENTS ARE EQUAL PARTNERS with professionals in the development of their child's full potential, that they are the AUTHORITY on their own child, and that they have the following rights:

1. the right to claim their just share, in partnership with their professional helpers, in planning their child's future.

2. the right to be informed of their rights.

3. the right to question decisions made concerning their child, especially when they do not agree with these decisions.

4. the right to all the services for their handicapped child that the law grants them.

5. the right to an appropriate education for their child at public expense

6. the right to inspect and challenge the contents of their child's school records.

7. the right to challenge any professional decision with which they do not agree.

8. the right to a due process hearing when they do not agree with school placement decisions.

9. the right to ask that their child receive all the benefits and privileges granted to average children.

10. the right to make mistakes without feeling guilty.

Parents often express feelings of ignorance, intimidation, guilt, defensiveness, frustration, anger, bewilderment, helplessness, and feelings of being patronized, condescended to, and overwhelmed, in their meetings with professionals.

THESE FEELINGS ARE ALL FEELINGS OF NON-ASSERTION. Parents need to be more assertive if they are to be effective advocates on behalf of their handicapped child, and if their child is to receive the services he/she is entitled to by law.

2
Assertiveness is...Assertiveness is Not...

ASSERTIVENESS IS:

1. expressing your needs clearly and directly
2. expressing your ideas without feeling guilty or intimidated
3. sticking up for what you believe your child needs - even though professionals may not agree
4. knowing your rights and how to get them
5. documenting what your child needs and all facts pertaining to his/her case
6. treating professionals like a partner
7. effective communication
8. conveying your feelings of self confidence when you communicate with others
9. advocating effectively on your own behalf
10. self reliance and independence
11. persisting until you get all the services your child needs
12. analyzing a problem and pinpointing area of responsibility before you act
13. agitating to get necessary legislation passed and get it implemented
14. organizing for change
15. having a positive attitude at all times

ASSERTIVENESS IS NOT:

1. beating around the bush before stating your needs
2. feeling too guilty or afraid to express your needs
3. agreeing with professionals - no matter how you feel - because"professionals know what's best"
4. ignorance about your rights
5. leaving everything to others because "they know how to do these things"
6. apologizing when asking for what is rightfully yours
7. ineffective communication
8. begging for what is legitimately yours by law
9. abdicating to others your right to advocate on behalf of your own child
10. reliance and dependence on others
11. giving up when you run into red tape
12. acting precipitously before you get all the facts
13. letting the politicians "take care of laws and all that political stuff"
14. acting "only" on your own behalf
15. giving in to defeat

3
Assertive and Non-Assertive Statements

ARE YOU AN ASSERTIVE OR NON-ASSERTIVE PARENT? READ THE FOLLOWING STATEMENTS; THEN DECIDE.

NON-ASSERTIVE STATEMENTS

"I wish they wouldn't take so long getting my child into a program."

"Mrs. S. is always so nice when I talk to her about getting my child into a program. She's very sympathetic about my having waited for nine months."

"I better not ask them again about services - they'll think I'm too pushy."

"Everytime I call the special education department, they're too busy to talk to me. I better not call again."

"My child needs services, but I don't want to push too much. They'll think I'm a trouble maker."

"I don't think I can go to the meeting. I never go anywhere after dark."

"I don't think this program is right for my child - but it's better than nothing."

"I'm only a parent."

"I'm not sure I agree with what the professionals want to do about my child. But I better do what they say. After all, they're professionals. They ought to know."

"I don't understand anything about this P.L.94-142. After all, I'm not a lawyer."

"It's OK if the school decides what should be in my child's IEP. Professionals know best."

"It's better if someone else represents my case at the Due Process Hearing. I'm too closely involved."

"If I stick my neck out and rock the boat ... they'll take it out on my child."

"Our school district has such financial problems, I can't possibly ask for the services my child needs. They'll say "no" for sure."

"I'm too emotional to deal with this. After all, I'm a parent."

"Those parents are so pushy. They're making enemies everywhere."

ASSERTIVE STATEMENTS

"I've waited long enough. I'm setting a deadline."

"Mrs. S. is always very nice when I talk to her about getting my child into a program. But I've waited nine months now and nothing has happened. I'm setting a deadline. Then I'm filing for a Due Process Hearing."

"If they think I'm pushy because I keep asking about services - then I'll have the kind of reputation that brings action."

"Every time I call the special education department, they're too busy to talk to me. I have documented that I have called them 5 times during the last two weeks. I'm going to report this to the school board at its next meeting, to the state Department of Special Education, and I'm going to insist on their being made accountable."

same as #3

"Sure, I'll go to the meeting - even though I don't like to go out at night - if it's important for my child."

"I don't think this program is right for my child. And I will not accept a program that is not appropriate."

"I'm a parent. And I am the authority on my own child."

"I will obtain outside recommendations regarding my child's needs and request a meeting to amend the IEP immediately.

"I don't understand anything about P.L.94-142. And I intend to find out everything I need to know. Where can I go for Parent Rights Training?"

"I intend to participate as a partner with the school, in the development of my child's IEP as the law requires - my contribution is just as important as the school's contribution.

"I'm getting parent rights training so I can represent my own case at the Due Process Hearing. I will also bring other parents for support."

"I'm willing to stick my neck out to get the services my child needs. And I won't allow anyone to punish me or my child for doing what's right."

"Our School District has severe financial problems, but I intend to ask for the services my child needs which he has the right to by law. He'll never get services if I don't. And the schools will never get the money they need if I don't insist."

"I'm qualified to handle this. I'm the parent."

"Those parents are really getting things done."

4
Being Assertive is Not My Style

"Being assertive is not my style."

IF BEING ASSERTIVE IS NOT YOUR STYLE - WHAT IS YOUR STYLE? ARE YOU A:

1. "NICE LADY" - who is afraid to say anything or do anything that might offend anyone - especially bureaucrats, because they will call you other names instead of "nice lady"?

2. "WHINER" - who constantly whines and complains about:

   a. the services your child needs and is not receiving?
   b. how bureaucrats treat you when you ask for services?
   c. how professionals treat you when you try to discuss your child's progress (or lack of progress)?
   d. how bad everything is - but never does anything about it?

3. CLINGING VINE - who clings to others and expects them to stick up for your rights and intervene on your behalf (or your child's)?

4. SILENT VICTIM - who has resigned herself to lack of needed services because "there's nothing I can do about it".

5. FAIRY PRINCESS - who expects everything to happen, and every service to be delivered without any effort on your part?

6. WAITER - who waits for a miracle to happen, for something someone promised, who waits and waits and waits for someone else to do something?

7. BOMBSHELL - who fires angry missiles sporadically, instead of calmly and methodically building a good case for what your child needs?

8. SCAREDY CAT - afraid that "if I make trouble they'll take it out on my child"?

9. APPEASER - who compromises her child's needs because "if I ask for too much they won't give me anything"?

10. PUT DOWN PARENT - who puts down other parents who are assertive.

11. SELL OUT PARENT - who makes deals with bureaucrats to get services for her own child and pressures other parents not to rock the boat.

If assertiveness is not your style and you are satisfied with your life and the services your child is receiving...

If you want to be known as a "nice lady", no matter how much it costs your child in services...

If you would rather whine and complain about "how awful everything and everyone is"...

If you want to cling closer to others and continue to depend on others to do everything for you - instead of learning how to do it for yourself...

If you are resigned to lack of services for your child...

If you want to go on believing in fairy tales...

If you would rather shoot angry missiles instead of doing something constructive...

If you want to keep on being afraid and letting others intimidate you instead of making them accountable for what they are required to provide by law...

If you would rather appease school officials and other bureaucrats - instead of fighting for the services your child needs...

If you would rather put down other parents who get services for their children by being assertive...

If selling out other handicapped children doesn't really bother you...

If you would rather just wait and wait instead of making things happen...

IF ASSERTIVENESS IS NOT YOUR STYLE AND YOU'RE SATISFIED WITH THE WAY THINGS ARE, THIS BOOK IS NOT FOR YOU.

If you feel compelled to continue your non-assertive style because "that's the way I've always been, that's how others expect me to act, and I can't change", THIS BOOK IS NOT FOR YOU.

But if you're not satisfied with the responses you've been getting in your quest for services; if you're tired of all those "no's and can't's" you've been hearing; and if you really want to do something about it - THIS BOOK IS FOR YOU.

Instead of being a "nice lady", you can become known as "that lady who really gets things done" (and other names which will mean the same thing).

Instead of a whiner you can become a doer.

Instead of a clinging vine you can become your own advocate.

Instead of a silent victim, you can become a fighter who fights City Hall.

Instead of a fairy princess, you can decide what you want and go after it.

Instead of a waiter, you can be an initiator who maps out a plan of action and implements it.

Instead of a bombshell, you can be an assertive parent who demands her rights in a forthright manner without losing her cool.

Instead of being a "scaredy cat", you can be a confident, assertive parent, who gets the services her child needs because she won't let anyone intimidate her into silence.

Instead of an appeaser, you can fight for your child's rights.

Instead of a put down parent - you too can get services for your child by being assertive.

Instead of a sell-out parent - you can join other parents in agitating for services for all handicapped children.

EVEN IF ASSERTIVENESS IS NOT YOUR STYLE, HAVEN'T YOU BEEN ASSERTIVE ON OCCASIONS WHEN YOU:

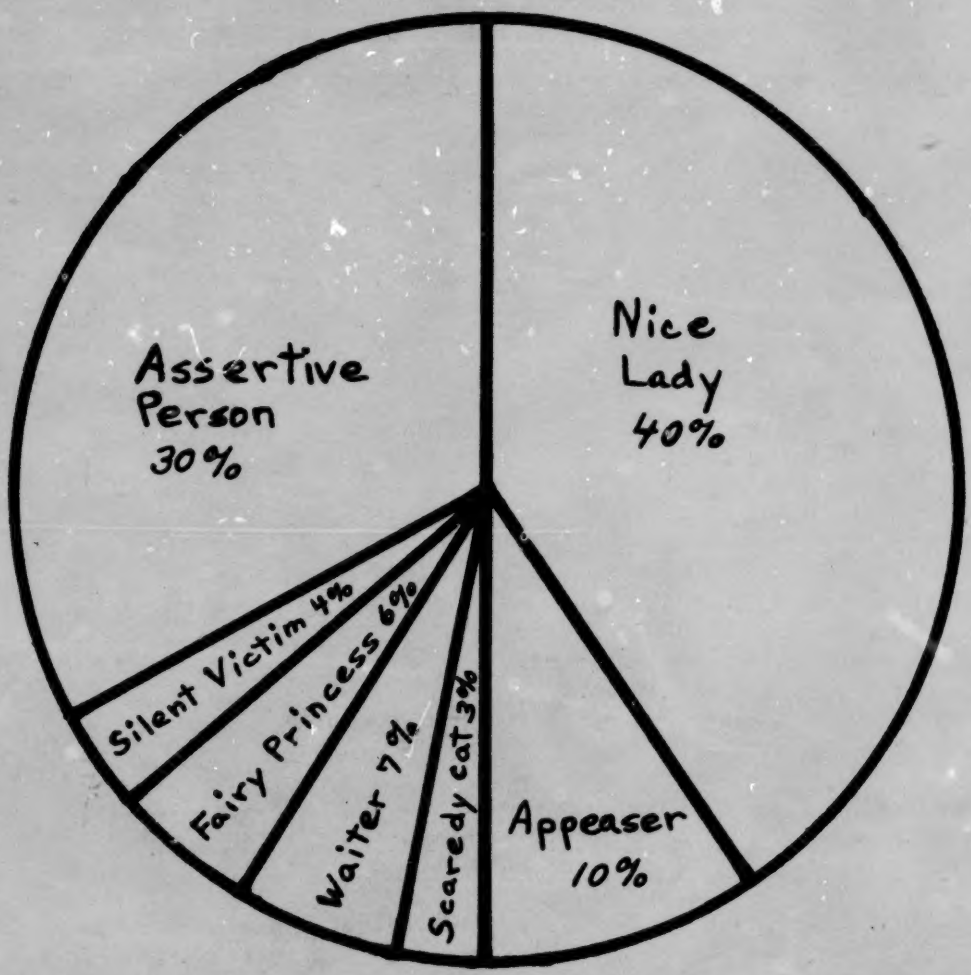
1. complained to the butcher about bad meat?
2. returned merchandise which was unsatisfactory?
3. complained about being short-changed?
4. brushed off a persistent salesman?
5. said "no" to unreasonable requests from your children and others?

If you answered "yes" to any of these questions, you can be assertive when you feel it's necessary. And aren't services for your handicapped child just as important as getting good meat, or good merchandise?

If you'd like to find out which of the above descriptions apply to you, draw a large circle on a sheet of paper and divide it into 12 unequal parts. Then, decide how much time you spend each week (and fill in the wedges accordingly) as a:

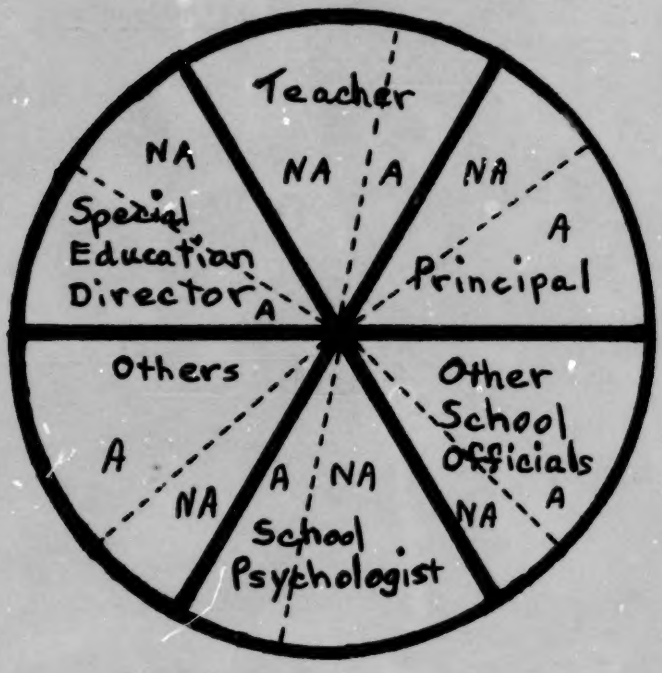
a. nice lady
b. whiner
c. clinging vine
d. silent victim
e. fairy princess
f. waiter
g. angry bombshell
h. assertive person
i. scaredy cat
j. appeaser
k. put down parent
l. sell out parent

EXERCISE #1: Make a circle and divide it into 12 unequal parts like this:



Fill in the wedges with the amount of time you spend being a "nice lady", "whiner", etc. For example, if you spend 40% of your time being a "nice lady", put this in the big wedge; if you spend 10% of your time being a "waiter", put this in a small wedge, etc...

EXERCISE #2: Make another circle and divide it into 6 equal parts, like this:



Decide whether the time you spend in meetings concerning your child's services is assertive or non-assertive. Meetings with:

a. principal
b. special education director
c. teacher
d. school psychologist
e. other school officials
f. others

EXERCISE #3:

Brainstorm with members of your parent group - or other parents or friends. Go around the room, asking each one in turn to complete the following sentence:

I wish I were more ...

Ex. I wish I were more assertive; I wish I were more gutsy:

Repeat the exercise with a new sentence: I can be more _____ by _____.

Ex. I can be more assertive by being informed about my rights and insisting on what I'm entitled to.

You are what you think you are. Start thinking assertively and you will become the assertive person you want to be.

You can change - you will change. YOU WILL BE AN ASSERTIVE PARENT AFTER READING AND IMPLEMENTING SUGGESTIONS FROM THIS BOOK.

PART II

DEVELOPING YOUR POSITIVES — ELIMINATING YOUR NEGATIVES

5
How to Build Up Your Self Confidence and Develop a Positive Attitude About Yourself

" I wish I could be more assertive, but I just don't have enough self-confidence."

The better you feel about yourself, the easier it is to assert yourself and get services for your child. How can you feel good about yourself when you feel so downed by all those self appointed know-it-alls who constantly remind you of how little you know? Start replacing negative thoughts about yourself with positive ones. Replace all negative images with positive images. DON'T DEPEND ON OTHERS TO CONVINCE YOU HOW GOOD YOU ARE - CONVINCE YOURSELF

EXERCISE #1

Here's one way to do that. Get a legal size pad and draw a line in the middle. On the left side of the page, list all of your good points. Are you a good cook? Put it down. Are you a good housekeeper? Cheerful? Prompt? Good at organizing birthday parties? Dinner parties? Good bookkeeper? Hiker, biker? Good with children? Kind? Generous? List all of these good things on the left side of the page. Make two columns.

On the right side, list all of your negatives, or all of those things about yourself you are not satisfied with and would like to change. Which column is longer? The left one or the right one? If the left column is longer, congratulate yourself. If the right one is longer, don't waste any time feeling sorry for yourself and putting yourself down. Start doing something about it. Start doing something to make yourself into the kind of person you would like to be.

Start by making a third column. And a fourth. List all of the things you would like to change about yourself, all of the things you would like to improve. List all the changes you would like to make in your life, in yourself.

Then, number them, starting with the change which would be the easiest to accomplish. #1 is the easiest to do, #2 is next easiest, etc., #3, then in column #4, list the specific things you will do to effect the change.

Ex: Column #3: I would like to be a better speaker and communicate more articulately

COLUMN 3	COLUMN 4
better speaker communicate more accurately	I will be more articulate by taking a public speaking course
I would like to be more knowledgeable	I will be more knowledgeable by 1)attending Parent Rights Training Sessions given by _____ on _____ 2)studying P.L.94-142, federal and state Rules and Regulations on P.L.94-142; 3)by studying Section 504, and its Rules and Regulations

Now, start with #1 and get going.

EXERCISE #2

On another sheet of paper, draw another line in the middle. This time make a list of all the people who make you feel good about yourself. Opposite their name, write down why they make you feel good.((+) people)

Next - on another sheet of paper - write down the names of all the people who make you feel bad or uncomfortable and write down why. You will notice the people who make you feel good are: helpful, relaxed, non-judgemental, and build up your self-confidence. They give you good strokes!

You will probably find that people who make you feel bad or uncomfortable are: stiff, unbending, pompous, arrogant, judgemental, critical and put you down. They give you bad strokes. ((-) people)

To increase your feelings of self confidence, increase your contacts with people who give you good strokes, and limit your contacts with those who give you bad strokes.

Before you have an important meeting with school personnel and other officials, try to have some contact with the (+) group and avoid the (-) group.

USE THIS TECHNIQUE AS A GROUP PROJECT FOR YOUR PARENT GROUP. Share with each-other your good points, bad points, and those points you would like to work on. Then, support each otherin a group project to bring about those changes you want.

ATTEND PUBLIC MEETINGS AND START SPEAKING OUT. Start with small meetings and gradually work up to larger ones. Bring a notebook to the meeting and take notes on what the speakers say. Do you agree or disagree? Why? Do you have any questions? Jot down a few words about those points you would like to comment on.

During the audience participation time of the meeting, raise your hand and speak out. You don't have to make a polished speech. Just express yourself the way you would at home during an informal gathering of your friends. But make a point of expressing your views at least once (more often if you feel like it) at every meeting you go to.

You will probably be nervous, jittery and scared the first few times. But so is everyone. Keep on speaking out. Each time it will become a little easier, until you will realize at one meeting that you are no longer frightened, no longer uncomfortable.

BRING A BUDDY, ANOTHER PARENT, A FRIEND, A RELATIVE - WITH YOU TO GIVE YOU MORAL SUPPORT and make you feel more relaxed. Have the buddy critique your presentation, making a list of the good things you did, and those things which need improvement.

Do this with your parent group - with each one speaking out and getting feedback from others afterwards. Bring a tape recorder to these meetings. Afterwards, compare your presentation with those of others. Again, get feedback from others on your presentation.

Use a videotape in the same way. You might be able to borrow a videotape from a friend who is connected with a university or a business that uses videotape. (See Chapter 7, HOW TO PUT PUNCH IN YOUR SPEECHES)

FIND OUT WHEN YOUR LOCAL SCHOOL DISTRICT, DEPARTMENT OF MENTAL HEALTH OR OTHER APPROPRIATE AGENCIES ARE HAVING PUBLIC HEARINGS ON IMPORTANT ISSUES. Call/write ahead and request to be placed on the agenda to present testimony. (See Chapter 31, HOW TO STACK PUBLIC HEARINGS TO WIN YOUR BATTLES)

Start treating yourself as if you were someone special. Buy yourself a nice dress, or a nice suit; that nice dress you thought was too expensive; Go out to dinner with your husband or a special friend once in a while.

Start treating yourself as if you already were an assertive person - and soon you will be.

6
Let Your Body Say Positive Things About You

" I feel so uncomfortable at school meetings, I never know how to sit, what to do with my hands - or what to say."

WHETHER YOU REALIZE IT OR NOT, YOUR BODY IS SAYING THINGS ABOUT YOU ALL THE TIME - EVEN WHEN YOU DON'T OPEN YOUR MOUTH. What is it saying? Is it saying you are self confident, knowledgeable, optimistic, and have positive feelings about yourself and expect to win?

Or is it saying you have a low opinion of yourself, are uninformed, pessimistic - and expect to lose. Walk up to the nearest mirror - in your usual, natural walk. Then, stop, and look at yourself. Are you standing straight - with an air of self confidence about you - or is your body drooping, your shoulders slumping, and your head down?

Study your face for a moment. Is it relaxed, smiling, cheerful - or is it taut, haggard, and unfriendly?

Before you even open your mouth, your body is announcing to others that you are either a winner or a loser.

A WINNER:

1. Stands straight and looks people in the eye when speaking with them.
2. Sits down in a relaxed, but business-like manner.
3. Keeps eye contact with people he/she is conversing with
4. Takes the initiative in greeting others at a meeting and in opening the conversation.
5. Seats herself next to the most powerful person in the room
6. Doesn't wait for permission to speak before speaking up
7. Carries a brief case full of materials with her to meetings, spreads them on the table, and has the information she needs at her fingertips.
8. Is dressed appropriately in a business suit or dress.

A LOSER:

1. Slumps when she's standing and cannot bear to look at you when she's talking to you.

2. Sits down like she was sitting on eggs, afraid to move an inch lest she break them.

3. Is uncomfortable looking at you for more than an instant.

4. Is afraid to take the initiative in greeting people and waits for others to give her permission to say "hello"

5. Sits inconspicuously - away from persons she perceives as powerful or threatening.

6. Is afraid to speak unless spoken to and given specific permission to speak.

7. Never carries information or materials with her.

8. Is either underdressed or overdressed, for a picnic or a party- instead of for a business meeting.

PRACTICE BEING A WINNER. START REHEARSING WITH A NEW WAY OF WALKING, STANDING, SITTING, AND TALKING WHICH WILL LABEL YOU A WINNER .

7
How To Get Rid of the Shakes and Put Punch In Your Speeches

"Me, make a speech? Every time I get up to say something in front of people, my knees start shaking, my voice quivers, and my mind goes blank. I just can't make a speech."

EVERYTIME you say something in front of people? Do your knees shake and does your voice quiver when you talk to your family? To your friends? To other parents? Of course not. You feel comfortable with them, at ease, relaxed. And there's no reason to be frightened when you talk to them.

Who are you frightened of? And why? What do these people do - or say - that intimidates you? That makes you feel inferior? What do they know that you don't know?

Are you afraid of the school officials you come in contact with and othe bureaucrats? Do you feel they know so much more than you - that they are so much more competent than you are, so much more capable?

IF YOU WANT TO DO SOMETHING ABOUT IT - YOU CAN DO THE FOLLOWING:

1. Make a list of all the people you know who make you feel uncomfortable and ill at ease, using two columns.

2. Next to their names, write all the things they do or say that makes you feel uncomfortable.

EXAMPLE: Mr John Bureaucrat.	Puts me down, has a Masters' degree, makes me feel ignorant, uses jargon I don't understand.
Ms. Mary Bureaucrat	She knows so much more than I do; always says or seems to say: "You're just a parent; you don't know as much as I do."

What kind of list do you have in front of you? Notice how often the words "knows so much more than I do" "is so competent" "has xyz degrees" appears. Notice how often "puts me down","keeps telling me I'm only a parent" and similar remarks appear.

The message is: Making a speech gives you the shakes because you think the people you are giving the speech in front of , are better than you are; that they are better informed; better educated, more competent, more knowledgeable, have more poise, and more self confidence than you.

SO WHAT CAN YOU DO ABOUT IT?

You can start by teaching yourself all the things you think they know.

1. Know your rights and what schools are required by law to provide for your handicapped child.

2. Follow all steps outlined in Chapter 15 WHEN YOU KNOW IT - FLAUNT IT

3. Start flaunting your knowledge at every opportunity, and practice letting others know how much you know.

4. Start practicing at family gatherings and gatherings of friends.

5. Continue practicing at small group meetings, making a point of saying something at least once at every single meeting. Practice ahead of time what you will say, then say it.

6. If someone at the meeting says something which triggers a response from you - don't just say it to the person next to you. Say it to the whole group.

7. Follow all steps in Chapter 5 "HOW TO BUILD YOUR SELF CONFIDENCE"

8. When you feel comfortable, and knowledgeable enough, let your parent group know you are available to participate in panel dis-dussions and small group meetings. Let them know that you have made yourself knowledgeable, and that you are willing to share your knowledge and your experiences with others.

9. Get your Parent Group to give a Public Speaking Course as a Group Project.

10. Use this chapter as part of your text.

11. Make more formal speeches for your group. Plan and organize them by doing the following:

    A. INTRODUCTION

    Introduce what you are going to say, with only a sentence or two about the major points of your speech. Have a snappy, attention grabbing beginning statement, like: "Today we are spending $10,000 - $50,000 per year per child in our state institutions - because we were not willing to spend a few dollars to educate them a dozen years ago..."

B. PRESENTATION

1. Make your points, point by point

2. Substantiate, document, and give evidence to support your major points. Example: If you are making a point that there are not adequate or appropriate services for emotionally disturbed children (or learning disabled, or physically handicapped, etc...), get statistics from your local Department of Mental Health and Disabilities, or other appropriate local, state or federal agencies. To substantiate this claim, show how many mentally ill children need services vs. how many are receiving them. Find out how much is appropriated in the Dept. of Mental Health Budget for Emotionally Disturbed children and include those figures in your speech

3. Add punch to your figures. Make them mean something.

4. Talk about other children or other parents you know who are part of these statistics. Give illustrations of real cases to make your statistics come alive.

C. Don't use a canned speech (one that has been written word for word). Why should anyone come out to hear you when they could have just read your speech? Prepare a brief outline of your major points and speak from that, in a natural manner.

D. Dramatize your speech without turning it into a soap opera. Grab your audience by letting them know how much is at stake. Speak with emotion. Let them know how you feel. Let your speech move them to do what you are asking them to do. But remain in control.

E. Speak as naturally and as sincerely as you can. Don't try to sound like a professional public speaker. Natural, sincere speakers get listened to more often than professional public speakers.

F. Speak up. Take a deep breath and project your voice so everyone in the room will be able to hear you.

G. Look at the audience while you are speaking. Look at them as though they are people you already know - to whom you are about to give a message that is important to them.

H. If you are giving a talk on P.L.94-142, ask the audience to review P.L.94-142 with you. Ask them what an appropriate education means to them; what an IEP is all about; when to call for a Due Process Hearing, how to prepare for a Due Process Hearing, etc. You will soon have a very active audience who will find your presentation very interesting because they will be part of the presentation.

i. Don't ever apologize for your inexperience or put yourself down in any way during your presentation (When speakers do that, the audience will silently agree with them)

j. Wind up your speech with a punch. Briefly summarize your major points and hit your demands. Say it like you mean it. Ask - don't BEG - instead of "Won't you please...", say "Our children need..." "Our children must have..." "There is only one choice for responsible officials to make ... and that is..."

WHAT IF

Think about all the worst things that can possibly happen during your presentation and prepare for them.

"What if I forget what I'm going to say and my mind is a total blank?"

You may forget what you were going to say - but it's doubtful that your mind will be a total blank. You will be facing a crowd of people - or what seems like a crowd of people. And there will be things on your mind. Such as: why you are there. To help in some way - right? Then, say so. Ask your audience to tell you what they want, like: "I am here to help in some way. And I'd like to know what kind of help you need."

"I'd like to know what your problems are. Let's start with the people in the first row. Would you introduce yourself and tell me what motivated your coming to this meeting, and what kind of problems you'd like us to work on?"

Pretty soon, you will have so many people telling you about their problems, and what they would like done about them, you will have forgotten all about yours. And your speech will gradually come back to you, and you can weave it in bits and pieces, in the responses you give to questions and comments from your audience.

"What if I babble on and on and don't know what I'm saying or don't know when to stop?"

If you babble on and on, you will be doing what some of our best paid lecturers do, without being the least bit self-conscious about it. But if you want to do better than they do, and want to avoid babbling, you can do that by preparing an outline ahead of time of the important points you want to cover. Allow x number of minutes for each point - time yourself and consult your outline and watch to make sure you don't overrun.

"What if I say something stupid or embarrasing and make a fool of myself?"

If you say something stupid and make a fool of yourself, your audience will probably be laughing - a feat which many polished speakers find very hard to accomplish. Simply laugh with them and behave as though you said it on purpose, to entertain them.

"What if I bore everyone to death?"

There is no guarantee that you or the most experienced public speaker in the world will not bore somebody to death. But you can minimize the chance of doing so by giving a live presentation without reading your speech. Your audience will be interested in what you have to say if you say it naturally, and you are interested in it. They will care about what you have to say if you care about what you are saying; and you carry the message that what you are talking about is very important to you and to them. And, after you have said it once - stop. Saying the same thing over and over again, and taking an hour to say something that could have been said in 15 minutes is the surest road to boredom.

"What if I offend somebody or make people mad by what I say?"

If you make people mad, you will have succeeded in getting their undivided attention. Many professional public speakers do it on purpose for that reason.

BEFORE EVERY PRESENTATION

1. Rehearse your presentation before friends or members of your group. Ask them to critique your presentation for: clarity, brevity, articulation, naturalness, sincerity, eye contact, poise, persuasiveness.

2. Tape your presentation and play it back. Make appropriate corrections, in style, content and body language.

3. Think of a specific occasion when you felt really good about yourself, when you felt self confident or powerful, and in control. Ex. When you had a successful birthday party for your children, or when your apple pie brought rave reviews at the PTA luncheon, etc... Think about this occasion, concentrate on it, minutes before you get up to speak. You will discover you feel more relaxed, and more self confident.

If you follow the above instructions you will soon become known as a dynamic speaker who inspires her audience to action.

8
How to Get Off The Guilt Trip

"Whenever I have meetings with professionals, I often wind up feeling guilty. I know I'm not to blame for my child's handicap, yet I often get the feeling that they (the professionals) think my child would not be handicapped or would do better, if only I were a better parent."

WHY SHOULD YOU FEEL GUILTY FOR TRYING TO GET HELP FOR YOUR CHILD? Isn't that why you went to the professionals? To get help for your child? Why should you feel guilty about that? Why should you feel guilty for being concerned about your child's welfare, for wanting the best educational services, the best treatment, the best psychological services?

Why should you feel guilty for looking ahead and trying to plan his future so he can live the best possible life and develop his/her fullest potential? Why should you feel guilty for being worried when things don't go right, and for getting angry when obstacles are thrown in your way?

Why should you feel guilty for expecting professionals to provide the services you are paying for through your taxes? And for getting angry when bureaucrats are not doing their job?

HOW DOES FEELING GUILTY HELP YOUR CHILD?

YOU CAN STOP FEELING GUILTY BY ACKNOWLEDGING THAT:

1. You have the right to get the best possible help for your child.

2. You have the right to insist on quality services for your child.

3. You have the right to get everything you are paying for.

4. You have the right to complain when you don't get what you are entitled to for your child.

Of course you would like to be a better parent. Who doesn't? Everyone - including those who are intimidating you - would like to be better parents and do more for their children. Do you know for certain that "they" are better parents than you are? Do you know for certain that "they" would be able to do better with a child like yours? Do you know for certain that "they" would be more effective in dealing with bureaucracies and with professional guilt inducers? Do you know for certain that "they" never make mistakes, that "they" don't ever feel guilty about <u>anything</u>?

If you ask yourself these questions - or better yet - ask "them", you will find that the people who are intimidating you and making you feel guilty, are not any better than you are, after all. So why let them intimidate you?

DON'T WASTE TIME FEELING GUILTY. Don't waste time with a lot of "if only's.." Start helping your child today. Start helping him/her by being an assertive parent who can get the services your child needs.

1. Get involved in a parent group. Write CLOSER LOOK, P.O.Box 1492, Washington, D.C. 20013 for the name and address of your local parent organization, if you're not sure.

2. Meet and talk with other parents. Support each other- but don't stop there.

3. Become an active member of the group by joining a committee. If there are no committees, form some. (See HOW TO ORGANIZE AN EFFECTIVE PARENT/ADVOCACY GROUP AND MOVE BUREAUCRACIES, published by CCHC)

4. Join in letter writing campaigns to get better services. Join in lobbying efforts to get necessary legislation passed and implemented.

SOON YOU WILL BE TOO BUSY TO FEEL GUILTY. And you will be feeling good about yourself because you will know you are doing everything you can to help your child.

9
How To Get Out of the Intimidation Trap

" I'm afraid if I stick my neck out and rock the boat to get services for my child, that they'll take it out on my child."

IT'S QUITE POSSIBLE THAT "THEY" WILL - IF THEY CAN COUNT ON YOU TO DO NOTHING ABOUT IT. But, if you have established yourself as a person who will make "them" accountable for their actions - and will report their intimidating actions and file appropriate complaints - do you think they will dare?

The best way to deal with the Intimidation Trap is to make "them" more afraid of you than you are of "them". When verbal threats are made, immediately write them down and repeat them to the speaker (as described in Chapter 10 HOW TO PUT DOWN THE PUT DOWN) to confirm their accuracy. If the threatener does not take back his remark, immediately file a written complaint to the official's superiors, with a copy sent to the offender. If this does not bring results, file a written complaint to state, then federal officials (BEH, OCR - see Appendix)

If the threats persist, report them to the press, again in a factual letter, with dates, actual quotes, etc... and copies of the letters to the offending official. For maximum effectiveness, complaints must be filed immediately - so that there are immediate consequenses to the threats.

IF YOUR CHILD - OR OTHER CHILDREN - REPORT INCIDENTS OF PHYSICAL OR VERBAL ABUSE, DO THE FOLLOWING:

1. Contact other parents of children involved. Inform them of your child's report and invite them to a meeting to discuss your child's report and those of other children and/or parents, to formulate a plan of action. Convey to them how bad it is for all children to go to school in an environment where abuse is allowed.

2. Ask these parents to contact others and invite them to the meeting.

3. If you don't know any other parents, ask your child for the names of other children he knows, their approximate addresses, and look up their names in your local phone book. Your child will probably know at least one or two other children. And their parents will know two or three others, etc.

4. AT THE MEETING:

   a. discuss the report and ask the parents if they have similar reports from their children

   b. write a factual report of all incidents, with names, dates, places, etc...

   c. decide on a course of action, going through appropriate channels.

5. The Course of Action can be:

   a. a group meeting with the school principal to discuss the problem, to present the written report; and to ask the principal to conduct an investigation, and take appropriate action (remember, the principal is the first agent of responsibility)

   b. If the principal is not responsive, take your complaints- in the same manner described above - to the district superintendent (send copies to the principal).

   c. If the District Superintendent is not responsive, take your complaints to state officials, to the State Special Education Director; send copies to the District Superintendent and to the principal, and to the State Supt. of Education.

   d. If state officials do not respond, file a written complaint to the Federal Government, to the Bureau of Education for the Handicapped, the Office of Civil Rights, etc...(see appendix for addresses)

   e. At the same time as you file your written complaint to Federal officials, take your case to the Press.

      1. write a letter to the Editor, to your local newspaper, documenting the abuse and documenting all your unsuccessful efforts to stop the above by going through "channels". Ask the newspaper to conduct an investigation. Send a copy of your Letter to the Editor to a, b, c, d, and e above.

   f. Ask your Parent organizations to get involved; involve them in g, h, i, and j, below:

   g. Take your complaint to your local school board. Ask to be placed on the agenda of the next meeting. Everyone in your group should do likewise and testify at the School Board Meeting, and report on the incidents of child abuse they have witnessed.

h. Follow all steps outlined in Chapter 31, HOW TO STACK A PUBLIC HEARING TO WIN YOUR BATTLES

i. Take your complaint to the PTA. Ask to be placed on the agenda of the next PTA Board meeting and ask the PTA to conduct an investigation. Remind PTA members that any incident of abuse is bad for ALL children, whether they are handicapped or not, whether the PTA members' own children are involved or not. A school environment where child abuse is condoned is bad for all children - and all parents should take appropriate action to stop it.

j. If a-i have brought no results, take your complaint to your local legal aid and/or Protection and Advocacy System. Ask them to take appropriate action.

k. or hire a private attorney to take appropriate legal action either as a group or as an individual.

10
How to Put Down the Put Down

"Whenever I assert myself, and demand service for my child - I get put down."

Do you want to do something about it? If you do - you can do the following:

1. Always bring your notebook with you (the notebook mentioned in the previous chapter) whenever you have an appointment with a bureaucrat. When someone puts you down verbally, immediately start writing - word for word - every word of the put down. Let him/her continue his put down to the very end - without interruption, and without a single word from you - but be sure to write every single word said to you. When he/she appears to be finished, confirm this by saying, "Are you finished, Mr. Smith?" If the answer is"yes", then say "am I quoting you accurately, Mr./Mrs. Smith?" (repeat every word you have written down). If he/she indicates there was a big misunderstanding, he/she did not really mean to say... (even though you may feel/know he/she really did mean it) Ask him/her for a "correction", then write down the correction "word for word". Then read back the correction, confirm its accuracy, and confirm that the misunderstanding has now been cleared up. Then drop the matter and continue with the meeting as businesslike as possible. You will have accomplished your purpose which is:

   a. to stop the put down
   b. to prevent future put-downs
   c. to let him/her know you are in control and will not tolerate put downs
   d. to let him/her know you will report putdowns to the proper authorities should they happen again

2. DON'T LET ANYONE PUT YOU ON THE DEFENSIVE - and NEVER, NEVER apologize for someone else's mistake or inaction - such as: "I'm sorry to bother you again about this, but ..." Why apologize because the bureaucrat didn't do something he/she is supposed to do, and you have to keep calling about it? It's not you who needs to apologize for that.

3. KEEP YOUR COOL. The cooler you are, the better impression you as an informed parent who is confident and in control.

4. KEEP YOUR COOL EVEN IF THE BUREAUCRAT LOSES HIS/HER COOL. If you keep your cool while the bureaucrat loses his/her temper, you gain points for your side. And you are now in control. It doesn't mean that you have lost the battle if the bureaucrat loses his/her cool. It just means that the bureaucrat is not professional enough to keep his/her self-control.

REMEMBER - THE ONE WHO KEEPS HIS COOL IS THE ONE WHO IS IN CONTROL. If you keep your cool you will be the one in control.

5. PRACTICE AND REHEARSE YOUR INTERRACTION AND YOUR ROLE with bureaucrats before you have a meeting with them. Anticipate what they will be saying, the arguments they will bring up - then practice an appropriate response with other parents or friends and relatives. If you rehearse enough, the appropriate response will be an automatic response - instead of an impulsive "Why did I say that?" response.

11
How to Get Around The Run-Around

"Whenever I try to get services for my child I get the run-around. I get shuffled from one person to the next - and each one tells me he doesn't have the authority to do what I ask or give my child what he needs."

IF YOU HAVE EVER VOICED THE ABOVE COMPLAINT, TRY THE FOLLOWING:

1. If you are in the school officials' office when he tells you it's someone else's job to get services, do the following:

   a. ask him the name of the person who has the responsibility, that person's address, phone, and area of responsibility, and their position.

   b. write down all the information above in your notebook

   c. ask him/her to call - <u>right now</u> - on the spot - the person just named, then immediately arrange an appointment with that person.

   d. if he refuses, simply walk to the phone and call him yourself. Don't ask for permission (you may not get it.) Remember that the phone is paid for through your taxes - and you have as much right to use it as the bureaucrat.

   e. don't leave until everything is straightened out - and the other person clearly acknowledges responsibility for providing the service you are requesting; or until you have an appointment with him/her to make specific arrangements for the service. If he refuses to accept responsibility, report back to #1 and make him responsible.

2. If you are getting the run around on the phone, get names, positions, departments and phone numbers of persons identified as having the authority to provide the needed service .

3. Confirm by letter that they really do have the authority.

4. Send copies of your letter to the referral source who named the responsible individual.

5. Follow all steps in Chapter 27 - <u>PUT IT IN WRITING</u>.

12
When They Call You Aggressive

"Whenever I try to buck the system and demand my rights I get called a pushy, aggressive, overly emotional parent. Or even worse."

When they call you aggressive and other names like "troublemaker", "agitator", "radical", "militant", "obnoxious", "hysterical", it usually means your message is getting through. You're making headway. YOU'RE WINNING, AND THEY'RE LOSING - AND THEY DON'T KNOW WHAT TO DO ABOUT IT EXCEPT CALL YOU NAMES. Like a bunch of sourpuss little kids who can't stand it when they lose, who say things like "you're ugly", "you're funny looking", "you're a dummy", "we don't want you in our club".

DON'T FALL INTO THE DEFENSIVE TRAP OR THE SILENT TRAP. Don't start defending yourself, insisting you're not "aggressive", "militant", "obnoxious", etc. Or worse - remaining silent when you should speak up - because you're afraid they'll call you names if you do.

If you're not sure whether you really are aggressive - take a look at the following AGGRESSIVE-DEFENSIVE STATEMENTS VS. ASSERTIVE STATEMENTS and see which ones describe the things you say:

AGGRESSIVE - DEFENSIVE STATEMENTS

1. "What do you mean my child has a learning problem? If he has trouble learning it's because you're not teaching him."

2. "My child is NOT emotionally disturbed. It's your fault that he's behaving the way he does."

3. "If you don't give me what I want right away I'm going to go to the newspapers."

4. "You really don't care about these children. All you care about is your paycheck."

5. "You haven't done a single thing to help my child. Why don't you get off your duff and do something? You're certainly getting paid enough."

6. "If there's no money for service, it's because you're overpaid!"

7. "If the state is in the red, it's because of all the money you and other politicians are stuffing in your pockets."

8. "Why do you keep blaming me for everything? It's your fault my child is having problems."

9. "What I do at home with my child is none of your business."

10. "How do you know what I'm going through, and all the problems that I have? YOU'RE NOT A PARENT!

11. "I don't care if you do have a program in the public schools. I want my child in a private school. Everybody knows how rotten the public schools are."

12. "The people working with my child are incompetent and lazy."

13. "Why does it always have to be the parents who get things done?"

ASSERTIVE STATEMENTS

1. "Thank you for letting me know about my child's learning problem. I'd like to know more. Could we set up an evaluation?"

2. "If you suspect my child is emotionally disturbed, I'd like to discuss this with you and other school personnel. Could we have a meeting on _____?"

3. "If you don't provide the services my child needs within the legally required deadline - I will institute a due process hearing."

4. "I expect that you took this job partly because of your concern for these children. Therefore, I hope you will ...."

5. "Nothing has been done in this case. The legally required deadline for services is _____ and I expect you to meet the deadline."

6. "If there's no money for services it's because this school district has set other priorities. I must remind you that P.L.94-142 requires these services and that federal funds will be withdrawn if you do not provide them, through Section 504 of the Rehabilitation Act."

7. Same as #6.

8. "I feel like I'm being blamed for my child's problems. Our focus should be on getting the services my child needs - not on placing blame."

9. "If you believe my home situation is aggravating my child's problem I'll think about it. Right now, I'm not sure about this."

10. "I don't think you understand everything that's involved in parenting a child like mine."

11. "I'm willing to visit the program in the public school and document the services it offers before I decide whether or not it's an appropriate program for my child."

12. "It seems that some new, innovative methods are needed to work with my child. Where can we get special education information and consultation regarding his specific problems?"

13. "We parents have worked hard to get laws passed; we intend to see that they're implemented.

If the things you say fall more in the AGGRESSIVE STATEMENT CATEGORY start rehearsing assertive statements which will carry your message in a more direct, positive manner.

If your statements are more like those in the ASSERTIVE STATEMENTS section, don't fall into the Defensive trap or the Silent Trap.

Remember, the bureaucrats wouldn't bother to call you anything if you were not effective. When people start calling you names, consider it a compliment. It means your message is sinking in, you're making headway. It could also mean that they feel threatened. And they think all it takes to silence you is to call you a few names.

Instead of falling into the DEFENSIVE TRAP or the SILENT TRAP, remember who is calling you those names and why. Let it spur you on to more action for your handicapped child.

13
Can You Really Listen?

Effective listening is an important part of assertiveness. It's also an important part of negotiation and communication.

Can you really listen when you are meeting with school officials and other bureaucrats?

To test your listening skills:

1. pair up with another person and have him/her speak to you non-stop for a full minute (about any subject matter)

2. repeat - as closely as possible to the speaker's version - what the speaker has just said to you.

3. have the speaker make appropriate corrections.

4. change roles - speaker is now the listener and vice-versa.

Did you listen intently enough, to be able to repeat the speaker's statement reasonably accurately?

Or did you find it hard to concentrate, with your mind wandering? Practice this exercise before your school meetings and negotiating meetings - so that you will be able to listen actively and get the most out of the meeting.

Also practice this exercise with other parents, with members of your parent group, and with professionals.

A parent-professional pairing is especially useful in this exercise. Each becomes more tuned to the thoughts, feelings, and problems of the other. This exercise will increase your listening skills. And when you improve your listening skills, you will find you are a better communicator, and better able to assert yourself effectively.

14
Bridging the Parent Professional Communication Gap

"Whenever I'm meeting with professionals I usually feel so frustrated, angry, guilty and helpless."

Did you know that when professionals have meetings with parents that they feel "frustrated, angry, guilty, and helpless"? This was documented at the 1979 IOWA ACLD CONFERENCE WORKSHOP where a group of approximately ten parents and fifteen professionals were separated (with all the parents together, and all the professionals together) into two groups and were asked separately to list their feelings during meetings with parents (in the professional group) and with professionals (in the parent group).

HERE ARE THE LISTS EACH GROUP CAME UP WITH: (In the order presented)

PARENT GROUP LIST: "When I'm meeting with professionals I feel ..."

a desire for honesty
run around
don't know too damn much
frustrated by jargon
anger
disgust
disappointed
defeated
guilt, guilt, guilt
overwhelmed
good
unsuccessful
trustful
respectful
sympathy
defensive
threatened

"I wish professionals were more... "

helpful
child oriented
concerned
knowledgeable
receptive to profession upgrading
humanistic
understanding
free to be open

"I like it when professionals..."

contact/communicate with me
listen to me
come with positive information
show respect for students
become involved in support groups
respect the knowledge of parents
individualize for students
share information
share professional knowledge
treat parents as equal

PROFESSIONAL GROUP LIST

"When I'm meeting with parents I feel..."

frustrated
professional liability
parents don't care
parents not very informed
uptight
threatened
insecure
pressured
patronized
tired, burned out
tense
upset
unsure
incapable of dealing with parents
unprepared
indignant
put down
successful
organized
confident
satisfied
knowledgeable
helpful
appreciative
fulfilled
accomplished
good about myself
needed
burdened with red tape

"I wish parents were more..."

better listeners
informed

"I wish parents were more..." (cont)

assertive
interested
less intimidated
reliable
initiating in dealing with problems
responsible
caring
involved
supportive
objective
better models
sensitive

"I like it when parents..."

ARE PERFECT
attend conferences, staffings...
follow through with suggestions
both attend meetings
see progress
provide feedback regarding the child's "performance"
are supportive of special services
are open with their communication
put their child's education first
show initiative in finding out what their child does in school
remember me at Christmastime
are honest
are objective
understanding of professional perspectives
are open minded

If you remember that professionals are experiencing the same feelings when they are having meetings with you, and that they too are "frustrated, uptight insecure, threatened, tense, upset, unprepared, put down, burdened with red tape..." you can meet them as partners, involved in the same meeting, sharing the same feelings, the same frustrations, the same fears.

Remember, when you are feeling frustrated, that they too may also be frustrated; when you are feeling angry, that they too may be angry; when you are feeling afraid, that they too may also be afraid; when you are feeling helpless, that they too, may be feeling helpless. A real partnership can develop between you and the professionals you are meeting with if you can share your feelings with eachother.

Use these exercises when you are meeting with professionals. You will both find them very revealing and beneficial.

15
How a Parent Group Can Help You Be Assertive

" I sometimes feel so alone as a parent. And I feel so overwhelm ! when I'm dealing with bureaucracies. Am I the only parent who' going through this?"

NO, YOU ARE NOT THE ONLY PARENT WHO'S HAVING PROBLEMS GETTING SERVICES . Many, many other parents share the same problems, and you need to meet them through a parent group. A parent group can help you be assertive by providing the information and support you need to get services for your child.

A PARENT GROUP CAN:

1. Let you know you are not alone with the problems you are experiencing in getting services for your child.

2. Inform you of your rights under the Education for All Handicapped Children Act (P.L.94-142) and Section 504 of the Rehabilitation Act of 1973.

3. Help you prepare for a staffing, IEP meeting, due process hearing, and other special education meetings.

4. Help you rehearse your presentation when negotiating for services for your child.

5. Provide support at staffings, IEP meetings, Due Process Hearings, and other special education meetings.

6. Help you file complaints with the U.S. Bureau of Education for the Handicapped, the U.S. Office of Civil Rights, when services required by P.L.94-142 and Section 504 are not being provided; or there is evidence that these laws are being violated in any way.

7. Help you lobby for more services, when the service your child needs does not exist.

8. Provide the emotional support you need to be effectively assertive and get your rights.

9. Negotiate with bureaucracies to rectify problems shared by the group.

10. Organize and participate in coalitions to reach mutual goals.

11. Participate with you in marches, demonstrations, picketing to reach your goals - when "going through channels" has failed to get desired results.

12. Give you the self confidence you need to fight for your child's rights.

13. Provide opportunities to share experiences, coping skills, negotiating skills and advocacy skills with other parents.

TO BECOME INVOLVED IN A PARENT GROUP AND/OR MEET OTHER PARENTS:

1. Contact your local chapter of the:

   a. Association for Retarded Citizens
   b. Association for Citizens with Learning Disabilities
   c. Parents of The Hearing Impaired.
   d. Parents of the Blind
   e. United Cerebral Palsy
   f. Spina Bifida Association
   g. Society for Autistic Children
   h. National Alliance for the Mentally Ill

For names and addresses of these parent groups:

   a. Consult the Not for Profit Organizations - Appendix
   b. Contact CLOSER LOOK, BOX 1492, Washington, D. C. 20013

If there are no appropriate parent organizations in your area, ORGANIZE ONE. Follow steps outlined in HOW TO ORGANIZE AN EFFECTIVE PARENT/ADVOCACY GROUP AND MOVE BUREAUCRACIES, published by The Coordinating Council for Handicapped Children.

PART III

ASSERTIVENESS AT SPECIAL EDUCATION MEETINGS

16
When You Know It...Flaunt It

" I feel so stupid when I talk to school officials and other professionals. They always tell me I don't know what I'm talking about, that they're the professionals, they're the experts; and that I'm only a parent."

If you feel stupid or ignorant when you talk to school officials and other professionals, it's probably because you are not as informed as you should be. You don't have to be a professional to be as informed as they are (or even better informed) - about your rights and what is required by law in services for your handicapped child.

START BY INFORMING YOURSELF ABOUT YOUR RIGHTS. INFORM YOURSELF ABOUT:

1. P.L.94-142 (The Education for All Handicapped Children Act)
2. Section 504 of The Rehabilitation Act of 1974
3. Family Rights and Privacy Act of 1974 (Student School Records Act)
4. Rules and Regulations on the above legislation
5. Your State Plan and State Rules and Regulations to implement P.L.94-142
6. Your state legislation effecting the handicapped.
7. Other federal legislation effecting the handicapped (see appendix)

You can find out about your rights by contacting:

1. your local parent/advocacy organization
2. The Coordinating Council for Handicapped Children
3. CLOSER LOOK
4. The U.S. Bureau of Education for the Handicapped (see appendix)
5. your state Office of Education
6. your local Office of Education
7. your local Department of Human Services
8. your congressmen
9. your state legislators
10. your local League of Women Voters
11. your local United Way public affairs department

All of the above organizations ought to be able to supply you with some or all of the legislation listed above.

Study all of the above material as though you had to take an exam on it. Underline all major parts as you go along - and also underline any specific material that is particularly relevant to your child's case.

Then write a summary of the material (if you have none) - or get someone to do it for you (your parent/advocacy group or other organization involved in services for the handicapped).

Let everyone know, you know your rights. Use props wherever you go. Bring all the above material whenever you have a meeting with a school official or other professional. Also, bring plenty of handouts (free material about the rights of parents)which you can get from your local parent group - or from CCHC, enough to hand out to all the people at the meeting. Spread your material all over the table - so everyone will see it. Invite participants at the meeting to help themselves to your free materials and tell them where they can obtain other materials displayed.

Let your body language convey that you know your rights and expect to get them. Let your stance, the way you sit (straight, but relaxed), the way you look at the other people (look them in the eye while you speak; don't turn your head and look away) convey the message that you are in control, that you are confident you will win your case. (See Chapter 6, LET YOUR BODY SAY POSITIVE THINGS ABOUT YOU)

Ask for your rights in an assertive manner which clearly conveys the message that you expect to get what you ask for. If anyone tells you they can't give you what you ask because it's against the law, or against the Rules and Regulations, or against school policy - ask them to show you which part of the law, etc.... before you accept their word for it.

By flaunting your knowledge, others will remember you as a parent who is knowledgeable and who knows how to use her knowledge. They will be more inclined to respect you and be responsive to your demands - than if you come across as an uninformed parent who does not know her rights and doesn't know what to do about it.

WHEN YOU DON'T KNOW IT, SAY IT. Don't be afraid to ask questions; that's how you'll learn the answers.

When you are hearing a talk - or listening to anyone explain anything which you don't fully understand - take notes and write down the questions you need answers to. At the end of the talk, ask your questions one by one. And be sure to write all the answers. Soon you will have enough knowledge to win the respect of others.

17
How To Be Assertive At Your Child's IEP

" At my child's IEP meeting, I was handed an IEP which was already all written up and I was told to sign it."

YOU HAVE THE RIGHT TO BE ASSERTIVE AND PARTICIPATE IN THE DEVELOPMENT OF YOUR CHILD'S IEP , AND NOT TO SIGN IT IF YOU DISAGREE.

Learn to use the IEP (Individualized Education Program) process as an effective tool to obtain appropriate special education and related services for your child.

P.L.94-142 (The Education for ALL Handicapped Children Act) mandates that a free appropriate education must be provided to all handicapped children ages 3 to 21. The IEP is the specific guidelines for your child's appropriate education. As a parent you are an important member of the team that formulates your child's IEP. You should know:

- how to prepare for an IEP meeting
- how to write your own IEP statement
- how to effectively represent your child at an IEP meeting
- how to deal with negative comments and criticism
- how to obtain appropriate special education and related services for your child

WHAT IS AN IEP?

P.L.94-142 (the Education for All Handicapped Children Act) guarantees a parent's right to participate in the planning of her child's IEP. You must always keep in mind that, as the parent, you know your child better than anyone else. Professionals may be the experts on current theories and educational practices, but you, the parent, are the expert on what has been occurring with your child on a day to day basis from the time he/she was born.

According to federal law, you must be notified of the date selected for the IEP meeting, time, location, purpose, and who will be in attendance. You are also entitled to ask that the meeting be rescheduled at a mutually convenient time, if you are unable to attend on the preselected date.

The IEP must state the specific special education services your child will need. For Example: one hour resource room daily; self-contained classroom for the autistic, using simultaneous communication, intrusion, relationship and behavior therapy. The extent of your child's participation in the regular education program should be stated, also. For Example: attendance in a regular social studies class, physical education class, and art class.

According to P.L.94-142, necessary transportation services and vehicle adaptation must be included in the IEP.

The meeting should begin with a report of your child's present level of functioning. His/her weaknesses and strengths should be discussed. From this the professionals (usually the teacher) and the parent(s) together should formulate the annual goals for the coming year, and the short-term instructional objectives for the immediate future (the next two to three months).

AN ANNUAL GOAL IS A GENERAL STATEMENT OF DESIRED CHANGE AND PROGRESS TO BE WORKED TOWARDS THROUGHOUT THE YEAR. FOR EXAMPLE: to improve self-help skills, to eliminate self-destructive behavior, to improve understanding of basic math concepts. The number of annual goals is determined by the nature and severity of the handicap. Generally, there are about five.

A SHORT-TERM INSTRUCTIONAL OBJECTIVE IS A SPECIFIC STATEMENT REGARDING CHANGES AND PROGRESS TO BE ACHIEVED DURING THE NEXT TWO TO THREE MONTHS. This is to include the materials and methods that will be utilized, how often, and for how many minutes the objective will be worked on; also, what criteria and evaluation procedures will be used to determine to what extent each goal has been achieved.

(1) FOR EXAMPLE: TO TEACH THE CHILD HOW TO BUTTON HER COAT. The child will be required to attempt to button her coat before leaving the school on a daily basis. The teacher will assist the child, only after the child attempts to do it herself. The teacher will reward the child with praise for trying. The child will also work with a big button doll for 3 minutes, 3 times a week with assistance and verbal reinforcements from the teacher. Criteria for completion of the goal will be the ability to button the coat independently 90% of the time.

(2) FOR EXAMPLE: TO ACHIEVE UNDERSTANDING OF ADDITION IN ONE DIGIT EQUATIONS. One-to-one assistance for 10 minutes each day using math Level 1 flash cards, supplemented by the Level 1 workbook for 10 minutes daily; ten minutes of small group (4 to 5) math work using the board will be provided daily. A homework assignment of 5 math problems to be monitored by the parents will be given 3 times a week. The criteria for completion of the goal will be on an 85% correct score on weekly review tests.

YOUR CHILD IS ENTITLED TO RELATED SERVICES - that is, developmental, corrective, and other supportive services - that are required to assist a handicapped student benefit from special education . The need for related services is determined by appropriate evaluation of the child's needs.

If you feel your child is in need of a specific related service, such as speech therapy, occupational therapy, physical therapy, recreation, counselling, etc., you should request an evaluation of that specific area.

The IEP should state each needed related service, the date of initiation of the service, and the anticipated duration of the service. It should also state how many times a week, and for how many minutes the service will be rendered, and by whom.

FOR EXAMPLE: SPEECH THERAPY FOR 20 MINUTES, THREE TIMES A WEEK; PHYSICAL THERAPY FOR 20 MINUTES DAILY.

When requesting needed related services, base your request on the premise that your child needs a given service in order to benefit from his/her educational program. If you feel that the recommendation for the related service by the school personnel does not accurately reflect the needs of your child, you may seek an outside evaluation.

Resources may be available in your community, or through a state agency at low cost or no cost to you. You may also be able to use your medical insurance to pay for a portion of the needed evaluation. You are entitled to obtain an independent evaluation at public expense if there is a ruling by a Due Process Hearing that the district's evaluation was not appropriate.

FOR EXAMPLE, YOU MAY FEEL YOUR CHILD NEEDS OCCUPATIONAL THERAPY. The school evaluates your child, and the recommendation is - no occupational therapy needed. You suspect that your child does need occupational therapy, but you know that your school does not employ an occupational therapist at this time. Therefore, you are unsure of the objectivity of its evaluation.

SEEK AN OUTSIDE EVALUATION, AND OBTAIN A RECOMMENDATION. If you get a recommendation for occupational therapy, request a conference to amend the IEP. Present your outside evaluation. If the school refuses to accept the results of the outside evaluation, file for a Due Process Hearing immediately.

(The above procedure can be followed when your child is receiving a needed related service, but the amount of time alloted for that service is inadequate.)

BEFORE THE IEP MEETING

1. Obtain a copy of the Federal Rules and Regulations on P.L.94-142 and your State Rules and Regulations (See Appendix). You can request a copy from the public school; the school is required to supply parents with a copy upon request. (However, many public schools are not aware of this, and do not have a supply of the Rules and Regulations) Read pertinent portions, underline the most significant sections, and make your own index. Use the language of the Rules and Regulations to represent your child. For example, avoid using the phrase "most appropriate " or the phrase "best educational environment".

Appropriate is the key word, and will enable you to represent your position adequately. Adding other words may open the door to word games that will only deflect from the focus of the meeting - - which is, an appropriate educational program for your child.

2. Prepare a written statement of your input for the IEP meeting. Make enough copies to pass out to all in attendance. Read the statement out loud. This will insure that all your concerns will be heard. Your statement should simply state the services, goals, and objectives you feel are appropriate for your child. You do not need to write the complete IEP, nor do you need to stipulate what types of materials will be used (unless you have a real preference). This should be done at the meeting. Your main objective is to present your views on your child's educational needs. (See a sample IEP Parent Input Statement following this chapter.)

AT THE MEETING

1 Do not go to the IEP meeting alone, It is common for parents to feel overwhelmed and alone when confronted with a room full of professionals discussing their child in a clinical manner. Invite other parents, friends, relatives, and anyone you know who might be interested in attending. Explain to them that you would like them to attend to give you moral support, and to function as witnesses in case of a disagreement.

2. The image you portray will effect how the school personnel react towards you. If you wish to be treated in a professional manner, you should dress in a professional manner. Choose clothing that is simple but dignified. Walk into the room with confidence. Don't wait to be acknowledged, but introduce yourself and begin greeting people as soon as you enter the room. Bring your copy of the Rules and Regulations with you and display it prominently on the table. Remember that it is your taxpayers'money that is paying for the salaries of the school personnel. They are working FOR you and your child.

3. It is a good business procedure to tape record the meeting. It will not be possible to take accurate notes in this situation, and personal notes can be disputed. Simply place the recorder on the table and plug it in. (Don't ask for permission) If someone expresses resistance, explain to them that it is a good business procedure to tape important meetings, such as this IEP meeting.

4. Pass around a sign-in sheet at the beginning of the meeting. You will then have the names of all those present, and be able to address them by name, (from their positions on the sign-up sheet) whom you are speaking to.

5. Follow all steps in Chapter 29, HOW TO NEGOTIATE WITH BUREAUCRACIES.

6. When speaking during the meeting, take a deep breath to help project your voice clearly and confidently. Maintain eye contact with the professionals while you speak.

7. When negative comments are made about you and your child, use these remarks to build your case for needed services for your child. (See Chapter 25, USING THEIR NEGATIVES TO BUILD YOUR POSITIVES)

8. Repeat what you are asking for whenever school personnel offer excuses or evasions. Remember that you are not there to discuss the limitations of the school budget. You are there to determine what your child needs to have an appropriate education. State this repeatedly, as often as necessary to make your point. (See Chapter 22, REPEAT! REPEAT! REPEAT!)

9. If school personnel state that there is a certain policy, rule, regulation, or law that requires them to take certain action or not to take certain action, do not feel intimidated. Ask to see in writing the specific policy, rule, regulation or law that they are referring to. Remember that federal law, and rules and regulations take precedence over state and local policies, laws, rules, and regulations.

IF YOU DO NOT AGREE

1. If you cannot come to an agreement, and you are running out of time. Or if you feel you need time to consider the situation, you have the right to request another meeting. Do not feel pressured to make a decision.

2. Most schools ask that you sign the IEP form. If you refuse to sign, the IEP can still be implemented as is. If you don't agree, simply sign your attendance sheet at the IEP meeting to document your presence. Specify that you are not in approval of the present IEP. For example: Anna Jones, present, but not in approval of IEP.

If school personnel refuse to include needed services in the IEP, inform them that you intend to file for a due process hearing and that you will file a written complaint with the Office of Civil Rights, Dept. of Health, Education, and Welfare, and write the Bureau of Education for the Handicapped (See Appendix)

Be sure to ask for a copy of the IEP. The IEP may be revised at anytime if you so request. It must be reviewed annually.

SAMPLE PARENT IEP STATEMENT:

PARENTAL INPUT ON THE INDIVIDUALIZED EDUCATION PROGRAM FOR JAMIE GREEN

- Placement in a class of 4 to 6 students with a teacher who is skilled in play therapy, intrusion therapy, consistency, and positive reinforcements. The teacher and the teacher's aid must be proficient in sign language.

- It is crucial that Jamie have contact with signing peers who can function as role models on a daily basis.

LONG TERM GOALS

- Increase in relating and socializing abilities.
- Increase in communication skills
- Improvement in self-help and survival skills
- Development of prevocational skills

SHORT-TERM INSTRUCTIONAL OBJECTIVES

- To increase relating and socializing abilities; intrusion/play therapy, using simultaneous communication should be provided for 30 minutes, 3 times a week on a one-to-one basis. Doll play, tickling, picture book sign language stories, etc., should be utilized.

- To increase communication skills; art therapy, utilizing drawing, should be used on a one-to-one basis for 20 minutes, daily. Jamie expresses herself through her drawings more so than through any other means.

- To improve self-help and survival skills: 40 minutes daily should be spent on activities such as washing dishes, bathing, and crossing the street.

- To develop prevocational skills: crafts should be used for 45 minutes, 3 times a week. The curriculum should include macrame, pottery, weaving, and basket weaving.

18
Gaining Access To ALL Your Child's School Records

" When I went to the school to inspect my child's school records, I was shown a thin file folder with only a couple of dozen inconsequential pieces of paper. I can't believe that this is all there is to my child's school records."

YOU HAVE THE RIGHT TO:

- Challenge the contents of the records
- Ask for correction or deletion of any inaccurate, misleading or inappropriate data
- Insert into the records a written explanation of your own about the contents
- Privacy as to the contents of the records
- Obtain copies of your child's school records at cost
- Designate, in writing, a person who may have access to your child's school records
- Receive an explanation of the contents by a qualified professional
- Control access and release of your child's records

To review your child's school records - contact the school principal and request to see your child's records. Federal law requires that the records be made available to you within 45 days of your request (your own state law may require a shorter time)

TO MAKE SURE THAT WHAT THE SCHOOL SHOWS YOU IS THE ENTIRE SCHOOL RECORDS FILE - DO THE FOLLOWING:

1. Make a written request asking that all school records at all locations be made available to you on _____ date.
2. Make a list of all the papers in the file.

3. Ask the principal to write you a letter - dated on the day you inspected the school records - confirming that the entire school record file includes (list all the papers found in the file)

4. Make copies of the Principal's letter and insert one copy in the file. This will protect you against paper reappearing later (after having been deleted by the school).

If you suspect your child's school records file has been tampered with, and school records destroyed without your consent - you have grounds for a Due Process Hearing.

19
How To Prepare For A Due Process Hearing

" I'm not satisfied with my child's present placement but the school district refuses to consider anything else. They refuse to include what I feel my child needs in services, in his IEP."

If you are not satisfied with your child's placement, and you disagree with the proposed IEP - or if you feel you have been denied any of your constitutional rights, you have the right to an IMPARTIAL DUE PROCESS HEARING.

WHAT IS A DUE PROCESS HEARING?

An Impartial Due Process Hearing is a special hearing set by the State Office of Education, where an impartial hearing officer hears both sides and renders a decision to the local education agency.

Your request for a hearing must be made in writing to your public school district superintendent. If you wish to challenge the placement of your child, your request for a hearing must be made within 10 school days of your receipt of notification of the proposed placement. Within 5 school days of your request for a hearing, the local school district will schedule a conference to review the case. Your participation and the participation of representatives of your choosing, will be an important part of this conference.

If the controversy cannot be resolved at this conference, a due process hearing will be scheduled. A certified letter requesting the appointment of an impartial hearing officer will be sent immediately to the State Office of Education, with a copy to the parents.

The hearing will be scheduled by the Hearing Officer at a time which is convenient to you and to representatives of your choosing (a lawyer, an advocate, another parent).

Your child will remain in his present program until the hearing has been held and a decision has been rendered.

The state appointed hearing officer's recommendation will be communicated to you, in writing, by certified mail within 10 school days after the hearing.

If you are not satisfied with the results of the hearing, you have the right to request a state-level review. You also have the right to appeal to the courts after other levels of appeal and communication have been exhausted.

BEFORE THE HEARING

1. BE AWARE OF YOUR RIGHTS. Find out what you are legally entitled to for your child in special education and related services, and the resources you have BY LAW if you are dissatisfied with a placement or proposed placement. YOUR RIGHTS ARE SPECIFIED IN P.L.94-142; Rules and Regulations on P.L.94-142; your state Rules and Regulations; The Family Rights and Privacy Act of 1974; and Section 504 of the Rehabilitation Act of 1973.

FEDERAL legislation listed above is available from: U.S.Office of Education Donahoe Building, 400 - 6th St., S.W., Washington, D.C. 20202; Bureau of Education for the Handicapped.
STATE legislation listed above is available from your state Office of Education.

2. READ AND CAREFULLY STUDY ALL MATERIAL IN #1 ABOVE. Study the material as if you were taking an exam on it. Underline and mark the material as you study. Especially underline and mark all the material that applies to your case.

3. VISIT THE PROGRAM THAT THE SCHOOL DISTRICT HAS OFFERED (which you feel is not appropriate for your child). Spend a whole day if you can. Take a notebook along and take notes that will help you document why the program is not an appropriate one for your child.

4. USE CCHC'S CHECK LIST / EVALUATION FORM FOR THE HANDICAPPED to help you evaluate the program (CCHC will send upon request in a stamped, self-addressed envelope)
5. INSPECT YOUR CHILD'S SCHOOL RECORDS. State and federal law gives you the right to:

    a. examine all information contained in your child's school records
    b. challenge the content of the records
    c. ask for correction or deletion of any inaccurate, misleading or inappropriate data
    d. insert into the records a written explanation of your own about the contents
    e. privacy as to the contents of the records
    f. obtain copies of your child's records at cost
    g. designate, in writing, a person who may have access to your child's records
    h. have your request to examine records granted within 15 school days.

6. OBTAIN AN OUTSIDE EVALUATION - if you haven't one already - at a reputable hospital or clinic which has a certified school psychologist on the staff. An evaluation by a reputable hospital or clinic will carry more weight than one done by a private physician, psychologist, psychiatrist, or neurologist.

7. OBTAIN A LETTER - ADDRESSED TO YOU - FROM THE HOSPITAL OR CLINIC which performed the evaluation, documenting why the proposed placement is not appropriate for your child, and making specific recommendations for a placement which agrees with your placement plan.

8. REHEARSE YOUR PRESENTATION. Try and anticipate all arguments that may be presented by school officials opposing your demands and rehearse appropriate responses.

AT THE HEARING

1. BRING ALL MATERIAL FROM #1 ABOVE TO THE HEARING, and display it on the table for everyone to see. (This will let everyone know you know your rights.) Be sure you have appropriate markers so that you can locate the information you need easily.

2. BRING RESULTS OF EVALUATIONS, LETTERS FROM PROFESSIONALS, AND ALL OTHER DATA DOCUMENTING THAT THE PROGRAM OFFERED IS NOT APPROPRIATE FOR YOUR CHILD.

3. BRING YOUR OWN REPRESENTATIVES TO THE HEARING, as you are entitled to by law. These can be:

   a professional who has evaluated your child
   a lawyer
   another parent, parent group representative, or advocate
   a community representative
   a friend or a relative.

4. AN INTERPRETER MUST BE PROVIDED if you are hearing impaired or if the language of your home is other than English.

5. A TYPEWRITTEN RECORD BY A COURT REPORTER OR A TAPE WITH TYPEWRITTEN TRANSCRIPT MUST BE MADE. You may receive a copy of the record upon request, at cost. You should also bring your own tape recorder, so that you have your own record of the hearing.

6. Follow all steps outlined in Chapter 29 HOW TO NEGOTIATE WITH BUREAUCRACIES.

REMEMBER!

THE IMAGE YOU PROJECT AND THE ATTITUDE YOU COMMUNICATE WILL PROBABLY INFLUENCE THE OUTCOME OF THE HEARING. It's important to communicate in a business-like manner and convey the message that you are informed and aware of your rights. Be positive and self-confident. An attitude that conveys the message that you expect to lose will not help you win. (See Chapter 6, LET YOUR BODY SAY POSITIVE THINGS ABOUT YOU)

20
Is A Lawyer Necessary?

IS A LAWYER NECESSARY TO HELP YOU WIN YOUR CASE? In a Due Process Hearing or other confrontation with a bureaucracy? In most instances - no - a lawyer is not necessary.

In many instances, a lawyer will be helpful. But sometimes, a lawyer is actually detrimental. A lawyer is helpful when:

1. He/she is thoroughly familiar with state and national special education statutes and their requirements.

2. He/she is thoroughly familiar with Due Process Hearing Procedures (or other procedures involving special education cases).

3. He/she is willing to extend himself/herself beyond the law and be a real advocate on your behalf.

A LAWYER IS DETRIMENTAL WHEN:

1. He/she is not knowledgeable in state and national special education statutes (or other appropriate statutes, such as mental health statutes, rehabilitation statutes, Section 504, etc..)

2. He/she is not familiar with Due Process Hearing Procedures.

3. He/she is not willing to extend himself/herself beyond the legal requirements to plead your case.

4. He/she is not willing to be a real advocate on your behalf.

Prepare and train yourself to be your own advocate (see Chapters 19 and 29). Study, take notes, and enlist the help of a local parent organization and/or local advocacy organization, to help you plead and win your case.

YOU SHOULD GET A LAWYER IF:

1. Your Due Process Hearing is at the Appeal Level.

2. Your problem involves dealing with the courts.

3. Your child is being transferred.

4. Placing your child requires giving up custody and/or legal guardianship.

5. You have tried appropriate strategies in this book, and your child is still not receiving appropriate services - or is at home without any services whatsoever.

WHEN SELECTING A LAWYER TRY:

1. Your local legal aid organizations. You will probably have to meet income eligibility requirements. However, legal aid may consider taking your case in a class action lawsuit or as a precedent setting case.

2. Your local Developmental Disability Advocacy organization. Federal law requires advocacy systems for DD in every state. Legal help is one of the services required.

3. Your local parent/consumer organization.

4. Your local A.C.L.U. (American Civil Liberties Union)

5. Private lawyers, other parents have used - who are knowledgeable in special education (P.L.94-142).

PART IV

ASSERTIVENESS EXERCISES FOR PARENTS

21
Assertive Responses For Those Old Excuses

Have you ever heard these excuses? Try out the Assertive Responses listed below the next time you hear them:

1. "There is No Money"

   Remember, there will NEVER be any money if you fall for this old line and accept the fact that there is no money. Whatever money there is can be reallocated and reprioritized. And legally mandated programs must come first.

   YOUR ASSERTIVE RESPONSE:

   "You will have to find the money somehow because the service is required by law, and if it's not provided the school district will lose millions in P.L.94-142 funds and other federal funds for other programs through Section 504 (of the Rehabilitation Act of 1973). This school has many activities that are not required. Since it has money for those activities, it can get money for mandated programs."

   or

   "You must be mistaken Mr...Obviously there is money to pay salaries of people who are employed here. Also, there is money for non-required activities like sports, drama, band. There must be money available for required services under P.L.94-142.

2. "You must be patient. These things take time."

   YOUR ASSERTIVE RESPONSE:

   "I have already waited _____for services. The law clearly states my child must receive services no later than the semester following determination of eligibility. I expect you to obey the law as I do."

3. "You must be realistic."

   YOUR ASSERTIVE RESPONSE:

"I am realistic enough to know that unless my child receives the services he needs, he will not be able to develop his full potential, and he will not be able to provide for his needs. I am insisting on the services he is entitled to precisely because I am realistic."

4."Don't be so naive."

YOUR ASSERTIVE RESPONSE

"Yes, I'm naive enough to believe public servants should fulfill their responsibilities. That's what my taxes pay them for. I'm naive enough to believe public servants must obey the law like everyone else."

5."You should be grateful your child is in a program. There are so many others who have nothing."

YOUR ASSERTIVE RESPONSE

"This program is not appropriate for my child. And P.L.94-142 requires an appropriate program for every child who needs special services. What my child needs is.....".

6."You're too emotional and too personally involved to really know what's best for your child. We are professionals. We know what's best."

YOUR ASSERTIVE RESPONSE

"You are the professionals, but I am the authority on my own child; I know him better than anyone else precisely because I am so personally involved."

7."I'm sorry about your problem, but there's really nothing I can do about it."

YOUR ASSERTIVE RESPONSE

"Apparently you are not aware that P.L.94-142 requires you to provide the services my child needs. Here's some material that explains what your responsibilities are, and the penalties for any school district which does not comply."

8."Do you expect us to change the whole school system just to accommodate your child?"

YOUR ASSERTIVE RESPONSE

"I expect you to obey the law and provide services for my child, required by P.L.94-142. Those services are.....".

9."Your child has severe emotional and learning problems. We feel that it would help if his home life was improved. Do you and your husband have sexual problems?"

YOUR ASSERTIVE RESPONSE

"I don't believe the purpose of this meeting is to discuss our sex life. However, if I'm wrong, I'll leave, so you can discuss my sex life all you want!"

Prepare a repertoire of appropriate assertive responses until they become part of your response vocabulary. Soon you will not only be responding appropriately verbally - but emotionally and psychologically as well.

22
Repeat! Repeat!! Repeat!!!

One of the most effective assertiveness techniques is the use of REPITITION. By repeating and repeating your message, over and over and over again, when you are given those same excuses, you will eventually wear down your opposition.

Repitition is a technique you probably use frequently with your own children when they make unreasonable demands, such as:

CHILD: All the other kids go to bed at 10 o'clock, and I want to stay up just as late as they do.

MOM: You know your bedtime is 9 o'clock.

CHILD: But all the other kids get to stay up until 10 o'clock.

MOM: All the other kids are not my kids. If they were, their bedtime would be just like yours. 9 o'clock.

CHILD: Why can't I stay up until 10 o'clock like the other kids do?

MOM: You know why you have to go to bed at 9 o'clock. You know you're always too tired in the morning when you go to bed later than 9 o'clock.

CHILD I promise I won't be too tired.

MOM: Your bedtime is 9 o'clock.

CHILD: I promise I'll get up on time and I won't be late for school.

MOM: You can make all the promises you want. Your bedtime is still 9 o'clock.

CHILD: But there's a terrific movie on tonight. Can I stay up just this once to watch it?

MOM: If your homework is done, and you want to watch the movie until 9 o'clock that's O.K. But your bedtime is still 9 o'clock, no matter what.

CHILD O.K. My homework is done, and I promise I'll watch the movie only until 9 o'clock. Then I'll go right to bed.

The same repetition technique illustrated above - which you have probably used in some form or other with your own children - is an effective assertiveness technique when confronted with officials who refuse to provide legally required services.

PARENT: My child needs speech therapy at least twice a week, for a minimum of 1 hour per session, according to evaluations by Children's Hospital and by the school. I'm here to enroll him in the speech therapy program.

SCHOOL OFFICIAL: Your child's name will be placed on a waiting list, and you will be notified when his turn is up.

PARENT: My child needs speech therapy now. P.L. 94-142 and State Rules and Regulations require that special education and related services be delivered no later than the semester following determination of eligibility. My child was declared eligible at an IEP meeting three months ago, and the new semester has already begun. Therefore, he must be served immediately. And I'm here to enroll him today.

SCH.OFF: But we have hundreds of children on our waiting list who have been waiting for months and months. Some for over a year. Are you saying we should let you ahead of those others who have been waiting so patiently?

PARENT: I'm saying that my child must be enrolled in the speech therapy program, as is required by law. And I'm here to enroll him today. It's the law. I can't understand why others are waiting for speech therapy when you are required by law to serve everyone.

SCH.OFF: That may be the law, but we don't have enough speech therapists. You'll have to wait like everyone else.

PARENT: I have already waited more than three months. My child must be enrolled today.

SCH.OFF: But you don't understand. We just don't have enough speech therapists.

PARENT: I understand. If you don't have enough speech therapists, it seems to me that you'll have to hire more. My child needs therapy, and I'm here to enroll him now.

SCH.OFF: We can't hire more speech therapists. We just don't have the money.

PARENT: You'll have to get the money somehow. If you have enough money for non-required activities like football, basketball, and drama, you should be able to find enough money for required services like speech therapy. My child must be enrolled today.

SCH.OFF: Somebody else takes care of that. It's not my department.

PARENT: Who is supposed to take care of it? Would you please tell me that? Would you please call that person here, so we can take care of it right away? (Write name and position in notebook) My child must be enrolled today.

SCH.OFF#2: We have a long waiting list for students who need speech therapy. There are hundreds ahead of you. We'll let you know when your turn is up.

PARENT: P.L.94-142 does not allow waiting lists. I'm here to enroll my child today.

SCH.OFF. #2: But we have hundreds of children who have been waiting for months. I know one or two who have been waiting for over a year. Are you trying to push your way ahead of all those children?

PARENT: I can't understand why hundreds of children have been waiting for months, when it's against the law. Apparently other parents have allowed their child to be placed on a waiting list. I won't. And I want my child enrolled today.

SCH.OFF. #2: Are you threatening me?

PARENT: I am notifying you that unless you enroll my child today, I will request an Impartial Due Process Hearing, today. (She takes out a sheet of paper and starts to write). Mr. Smith, what is your exact title (continues to write)...Very well, I will deliver a copy of my letter to the District Superintendant to you tomorrow morning. Good day. (She leaves)

The repetition technique will work if you are persistent, and repeat, repeat, repeat your demands over and over and over again, no matter what arguments your opponents bring up. Above all, you must not throw up your hands (either physically or figuratively) and give up in disgust. This is exactly what school officials and other bureaucrats are counting on when they keep telling you no, and give you dozens of excuses why they can't provide the services your child is entitled to.

23
How To Shovel Your Way Out of Those Bureaucratic Snowjobs

A common bureaucratic trick used to deny services and to turn down legitimate grievances is the indirect snow job approach, where there is no direct "no", but simply a big snow job that completely evades the parent's legitimate requests. Parents often experience this technique, not only with bureaucrats, but with their own children, as shown in the following dialogue.

PARENT: Now that we're finished with dinner, I'd like you to finish your homework.

CHILD: That was a crummy dinner. Why couldn't we have pizza instead?

PARENT: Maybe we can later this week. But, right now, I want you to finish your homework.

CHILD: That teacher always gives too much homework. Nobody can ever get it done.

PARENT: In that case, you'd better get started right now, so you can finish your homework before bedtime.

With school officials, the SNOW JOB APPROACH goes something like this:

PARENT: I'd like to have a summer program written in my child's IEP.

SCHOOL OFFICIAL #1: You want a summer program written in your child's IEP. We can't possibly do that. If we do it for you, all the other parents in the district will be after us to put it in their child's IEP.

PARENT: We are not here to discuss what other parents will be asking. We're here to discuss my child's needs and his IEP. He needs a summer program because he will regress if his schooling is interrupted. A summer program must be written into his IEP.

SCHOOL OFFICIAL #2: Do you realize how much a summer program would cost? Do you realize it would bankrupt this school district if we had a summer program for all the children here?

PARENT: P.L. 94-142 forbids financial considerations to play any part in determining what services a child will receive. The child's educational needs are the only considerations.

SCH.OFF. #2 That article in the local paper was highly inflamnatory, and its charges were completely false.

PARENT: I have no control over what the newspapers choose to print, and we're not here to discuss the newspapers. We're here to discuss my child's IEP.

SCH.OFF. #3 Your appearance at the school meeting was highly irregular. You made a fool of yourself by asking the impossible.

PARENT: We're here to discuss my child's IEP. We should confine our comments to my child's IEP.

SCH.OFF. #3: The parents you brought with you at the last meeting are very pushy, and they are jeopordising all the good programs we have in the district by their behavior.

PARENT: I would appreciate it if we could confine our discussion to my child's IEP. Here is the documentation that shows her need for the summer program.

SCH.OFF. #1: I see it comes from ABC Hospital. Are you involved in their family therapy program? I think you and your husband would benefit from it.

PARENT: That may or may not be true. But we are not here today to discuss my family problems. We're here to discuss my child's IEP.

SCH.OFF. #1: I think your child could also benefit from counseling, and ABC Hospital has a fine program.

PARENT: That may or may not be true. But the purpose of this meeting is to discuss my child's IEP and his need for a summer program - nothing else. Let's get on with our business.

24
How To Escalate Your Way To Services

Escalation is an assertiveness technique we have all used with different people, all through our lives - perhaps without even being aware of it. You have undoubtedly used it with your children, in a scene something like this:

PARENT: If you hit little sister one more time I'm going to send you to your room.

CHILD: But she started it. (hits her)

PARENT: All right. In your room you go.

(After the child is in his room, there is loud banging on the door, and the sound of toys being thrown around).

PARENT: Please be quiet and pick up all those toys you just threw around. If you don't do it right away, you'll have to stay in your room the rest of the afternoon.

This escalation technique is also effective when bureaucrats give you the runaround. The bureaucratic runaround is often referred to by bureaucrats as "going through channels."

EXAMPLE

PARENT: I'm here to enroll my child in special education services. We had a staffing six months ago. At that time I was told he would be in an appropriate program within a month. But, so far, nothing has happened.

SCHOOL OFFICIAL: Things have changed during the last six months. We've had a lot of cuts....

PARENT: I'm aware of that, and I'm also aware that P.L. 94-142 requires that my child be served no later than the semester following determination of eligibility. My child was determined eligible six months ago, and the new semester started four months ago. He was supposed to have started in a special education program at that time. I have a letter, here, which I wrote, requesting a Due Process Hearing. Since I have repeatedly requested services for my child, and you have repeatedly refused to provide them, I have no choice.

SCH.OFF: But it's out of my hands. We just don't have the money.

PARENT: Here's a copy of the letter. I'll leave it with you. I'm sure you will be notified of the date and time of the hearing. Good day.

SCHOOL OFFICIAL: Wait. Perhaps we can find a way... I'll contact the superintendent.

When using the ESCALATION TECHNIQUE, it's important not to make threats you don't intend to keep. A bureaucrat will find out (almost as soon as a child will) if your teeth are made of plastic,and if your growl is that of a paper tiger.

Never make idle threats. But do serve written notice of your intentions. And don't keep your intentions secret. Informing your opposition of your every move is part of the ESCALATION ASSERTIVENESS TECHNIQUE. It will give them a chance to respond positively to your demands before your action can be carried out.

25
Using Their Negatives To Build Your Positives

The negative building block assertiveness technique enables you to use negative statements (accusations, attacks) from your opponents to build your own case (instead of a defensive reaction).

EXAMPLE: (Defensive Reaction)

PARENT: The evaluations performed by the school and the XYZ Neurological Institute show that my son has a learning disability. I was told at the IEP meeting several months ago that he would receive special education services. But I find nothing has been done, and he is getting further and further behind. Please tell me when he will start in the LD Program.

SCHOOL OFFICIAL: We've had a lot of problems with your son. I get reports from his teacher all the time that he can't sit still and is very disruptive.

PARENT: What do you mean, he's very disruptive? He's no more disruptive than the other children.

SCHOOL OFFICIAL: Also, I happened to see some of the work when I visited his class recently. And he is doing very poorly. He's way behind the others.

PARENT: He's doing the best he can. He works very hard, as hard as he possibly can. What do you expect? After all, he has a learning disability.

SCHOOL OFFICIAL: I'm told that he also has emotional problems. Don't you think you should do something about it?

PARENT: My son is <u>not</u> emotionally disturbed.

EXAMPLE #2 <u>Same participants using Negative Building Block Technique</u>

PARENT: The evaluation performed by the school and the Neurological Institute show that my son has a learning disability. I was told at the IEP Meeting several months ago that he would receive special education services. But I find that nothing has been done, and he is getting further and further behind. Please tell me when he is to start in the LD Program.

SCHOOL OFFICIAL: We've had a lot of problems with your son. I get reports from his teacher all the time that he can't sit still and is very disruptive.

PARENT: I don't doubt that you have. That's why he needs an LD Program. (negative building block) When will he start? (repitition)

SCHOOL OFFICIAL: Also, I happened to see some of his work when I visited his class recently. And he is doing very poorly. He's way behind the others.

PARENT: You're absolutely right. He is doing very poorly. And I'm glad that you have observed, as I have, that he is way behind the others. That's exactly why he needs an LD program (negative building block) And he needs to start right now so he won't get further behind than he already is.

SCHOOL OFFICIAL: I'm told that your son also has emotional problems. Don't you think that you should do something about it?

PARENT: It's quite possible that my son has developed emotional problems as a result of the years of frustration he has had to endure because of his Learning Disability. You are right, I should do something about it. And that's why I'm here. (negative building block). As you have just stated, there are a lot of problems with my son's present placement: he has trouble sitting still in class, he's way behind in his work, and he's developing emotional problems as a result. You're absolutely right - we should do something about it - RIGHT NOW. As you have pointed out - his present placement is unsatisfactory. The only alternative is the Learning Disability Program.

26
The "No YOU Can't But I Can" Technique

A common put-down, and a common method to stop parent assertiveness, by bureaucrats and others who don't want to bother doing anything, is the old, "It can't be done" routine.

An effective way to deal with these native generalizations and to get out of the negative trap - is to personalize the statement and agree only with the fact that he/she personnally cannot - but that you can.

EXAMPLE:

BUREAUCRAT:	You can't fight City Hall.
PARENT:	If you say you can't fight City Hall, I believe you. But I can and I will.
SCHOOL OFFICIAL:	There's nothing that can be done for your child. We've tried everything, and nothing works.
PARENT:	I'm sure you've tried everything you know how, and you haven't been able to do anything for my child. It's time we tried another program somewhere else.
BUREAUCRAT:	Pushing never gets you anywhere. You have to make friends with people to get anything.
PARENT:	It sounds like pushing doesn't get you anywhere, and making friends does. But pushing for my rights has gotten services for my child that I was never able to get before.
BUREAUCRAT:	You catch more flies with honey than you do with vinegar.
PARENT:	I'm sure you do. But I'm not interested in catching flies right now. I'm interested in getting services for my child. And, I find that speaking up for my rights is accomplishing a great deal.
BUREAUCRAT:	It's who you know - not what you know.
PARENT:	Your're telling me knowing influential people has helped you. I find that knowing my rights has helped me more than anything else.

ANOTHER PARENT: When your child is in a good program, you don't need a parent group anymore.

PARENT: Apparently you feel you don't need a parent group anymore. But I continue to get a lot of information and support from my parent group - even though my child is now receiving excellent services.

PROFESSIONAL: You can't rock the boat, you know.

PARENT: Maybe you can't rock the boat. But I can. And I will, whenever I believe it will help my child.

BUREAUCRAT: If you want to get along, you can't make waves.

PARENT: You seem to be afraid to make waves. But I'm not.

NEGATIVE PERSON: Do you think you can start a parent group (or a coalition..) and move bureaucracies? Others have tried. And they've all failed.

PARENT: If that's really true, I'll probably be the first one to succeed.

BUREAUCRAT: That's impossible.

PARENT: Maybe it's impossible for you - but it's not impossible for me.

PART V

ASSERTIVENESS WITH BUREAUCRATS AND PUBLIC OFFICIALS

27
Put It In Writing

"Whenever I try to contact officials to get services, I never get anywhere. They're never available. And they never return my calls even though I leave a message every time."

"The school promised they would provide a program. Now they act as though they never did."

IF YOU PUT IT IN WRITING, you will have concrete evidence of your efforts to contact bureaucrats and of their promises. And if you send a copy to the bureaucrat's superiors, you will be making him/her accountable. When you contact bureaucrats by phone, there is no proof that the call was ever made, or that promises of services were ever given.

WHEN YOU PUT IT IN WRITING - send your letter by registered or certified mail - you will have concrete evidence of your efforts to reach the bureaucrat. You should put it in writing when you:

1. are asking for a service for your child.
2. are dissatisfied with a service
3. want to meet with school personnel or other officials
4. want to protest inadequate, inappropriate or non-existent services
5. want to file for a Due Process Hearing under P.L.94-142
6. want to appeal a School Decision
7. want to appeal a Due Process Hearing Decision
8. want to set a deadline
9. want to file a complaint about inadequate, inappropriate or non-existent services to the Bureau of Education for the Handicapped or the U.S. Office of Civil Rights.

You should also get officials to put it in writing when:

1. they are telling you your child cannot get services because there is a waiting list
2. they are making promises about services
3. they are giving you other reasons for not providing services your child needs.

PUT THE PROBLEM DOWN ON PAPER, IN THE FORM OF A LETTER ADDRESSED TO THE SCHOOL PRINCIPAL. Remember, the principal is the first person directly responsible for providing educational services for your child.

In your letter:

a. state the problem as clearly and as briefly as you can, but be sure to include all important information, stating the reasons why your child needs the services you are requesting. Use the language of the law when asking for services . Example, use the word "appropriate" instead of "best"

b. Use professional documentation (results of professional evaluations, etc...) to support your request.

c. Also include references to state and federal statutes (P.L.94-142, your State Special Education Law, the Federal Rules and Regulations, the state Rules and Regulations) to give your letter legal clout.

YOU SHOULD ALSO:

1. keep a notebook by the phone so that you can keep a record of everyone you talk to, their name, position, department, phone, etc.

2. keep a file of all correspondence, with several copies of every letter you send.

3. take careful notes at every meeting, conference, etc., that you attend, that relates to your child, so that you will have a record of all the information you get at these meetings.

SAMPLE LETTER

Name (of the Principal or other appropriate
Address official)

This letter comes to notify you of my intent to register my child _____ (child's name) for special education services as follows: (list services your child needs and why)

I understand that, as required by P.L.94-142, within thirty (30) days: a case study evaluation will be performed; a staffing will be held with my participation, to determine my child's eligibility for special education. An IEP meeting will then be held with my participation to formulate an Individualized Education Program for my child.

2. When requesting services for your child from the school psychologist:

   a. Ask the principal to make arrangements with the school psychologist for an evaluation and/or other psychological test for your child. Most psychologiststravel from school to school, and they provide services for children from several schools.

   b. Put the request in writing, clearly and briefly stating the reasons why you feel your child needs an evaluation and/or other psychological services.

To request social work services, physical therapy services, speech therapy, and other supportive services, follow steps in #1 above.

3. Follow up on your letter approximately 5 days after you have sent the letter to the principal or other school official. Call him/her up and remind him of the letter, and ask him/her when the service will be started.

IF YOU ARE NOT SATISFIED WITH THE RESPONSE. IF YOU ARE TOLD THAT:

   a. there is a long waiting list
   b. there is no program
   c. there is no money to open a program

...write a second letter, more forceful than the first, giving the principal a deadline, with copies to:

the Special Education Director, the district, and state Supt. ducation, The Bureau of Education for the Handicapped, The Office of Civil Rights (see Appendix for Addresses)

SAMPLE 2ND LETTER

Name
Address

This letter comes to notify you of my intent to file for a Due Process Hearing under P.L.94-142 within 10 days .... If my child does not receive _____ services he/she needs, which I requested on _____
(a copy of original letter is enclosed)

Within five (5) days, follow up your letter with a phone call asking when not if, the service will be provided.

28
How To Influence People Instead of Just Making Friends

" I think it's better to make friends with people instead of being assertive."

IT'S FINE TO MAKE FRIENDS. BUT FRIENDSHIP WITH BUREAUCRATS IS NOT LIKELY TO HELP YOU GET SERVICES FOR YOUR CHILD.

Which is more important? Getting help for your child - or making friends with those who are paid by you to help your child? Don't fall into the friendship trap. Friendship means being concerned with the other person's welfare, being careful by not saying or doing anything that might offend him/her.

Is the bureaucrat likely to put himself out/ stick his neck out - on your behalf and on behalf of your child because of your friendship? Or is the friendship likely to be a one way street with your side doing most of the giving?

Being friends with the bureaucrats who are responsible for providing services for your child means putting you in a conflict of interest position.

You will gradually find that your decisions - and your actions - are dictated not by your child's welfare, but by the welfare of the bureaucrat.

When you have exhausted traditional channels you will be reluctant to file for a Due Process Hearing because "this action may hurt Mr. S. and he is always so nice to me". You will delay making complaints to higher-up when services are not provided because "I really think they have done everything they can. It's really not their fault that nothing is being done." Or, "If she sticks her neck out and tries to do something, she might lose her job. I better not push too hard."

If a bureaucrat gives you what your child is entitled to in services, he is your friend. If he doesn't, he is your enemy. It doesn't matter how friendly, how nice a bureaucrat is, if he does not give you the services your handicapped child is entitled to, he is not your friend.

Many bureaucrats use friendliness and flattery as a form of intimidation, another way to keep parents quiet while they go about their do-nothing routine. Many parents fall for the "sweetness and light" routines. They

believe that the way to get concessions from bureaucrats is to have friendly relationships with them. But, when there is a friendly relationship, it's the bureaucrats who end up with most of the concessions.

Bureaucrats have all kinds of excuses why they cannot provide a service and do the job they are paid to do. If you are their friend, how can you not sympathize? How can you not understand? How can you not respond to their pleas and give them more time? Meanwhile you are sacrificing your child's welfare and letting him do without services he needs - because of your friendship with bureaucrats.

INFLUENCING PEOPLE - the people who are responsible for providing services for your handicapped child - will bring better results than just making friends.

YOU CAN INFLUENCE PEOPLE BY:

1. Being informed of your rights and the proper procedures to get your rights (see YOUR RIGHTS).

2. Flaunting your knowledge. Whenever you attend meetings with bureaucrats and public officials, bring copies of all relevant materials - and be sure to display all your materials on the table in front of you.

3. Bringing a tape recorder to all important meetings - to have an accurate record of the proceedings. Don't ask for permission. Simply turn it on.

4. Being an effective negotiator at meetings (See Chapter 29, HOW TO NEGOTIATE WITH BUREAUCRACIES)

5. Being persistent in your demands (See Chapter 22, REPEAT! REPEAT! REPEAT!)

6. Being assertive with your politicians (See Chapter 30, HOW TO ASSERT YOURSELF WITH THE POLITICIANS)

7. Being an effective communicator (see Chapter 7, HOW TO GET RID OF THE SHAKES AND PUT PUNCH IN YOUR SPEECHES)

8. Stacking public hearings to win your battles (See Chapter 31, HOW TO STACK PUBLIC HEARINGS TO WIN YOUR BATTLES)

9. Using the Power of the Press to help you get services (See Chapter 32, HOW THE PRESS CAN HELP YOU GET SERVICES)

10. Giving credit to officials who are doing a good job.

As a parent your only concern should be your child's welfare. Concern for

the bureaucrats who are paid by you to provide services for your child will only get in the way of reaching your goal which is: to get appropriate services for your handicapped child.

ALWAYS REMEMBER TO THANK OFFICIALS - publicly if you can - who are helping you and your child, especially those who are willing to stick their necks out and go that extra mile.

29
How To Negotiate with Bureaucracies

"I'd like to be more assertive with school personnel and other public officials, but I just don't know how."

WHEN YOU NEGOTIATE WITH BUREAUCRACIES, it's important to map out a Plan of Action ahead of time, whether you are negotiating as part of a group, or negotiating as an individual.

Negotiating as part of a group usually gets the best results because the pressure of the group and its potential power are always visible. There is also more accountability in group negotiations. Bureaucracies will be more inclined to grant your demands, to implement their promises, and to follow through - if demands are made by a group and if promises are made to a group.

If you are not already part of a group, contact other parents you know and discuss with them the potential benefits to their children of participating with you in your negotiations with bureaucracies. Contact parent organizations you know and ask them to participate also.

BEFORE THE NEGOTIATING MEETING:

1. Sit down with other members of your group and make a list of your needs and recommendations.

2. Rate your demands/recommendations in terms of priority. Ie. the most important will be #1, the next important will be #2, etc.

3. Identify the agent of responsibility , the public agency responsible for meeting your demands.

4. Write a statement incorporating your demands (without listing their priority numbers; keep those on a separate, private list). Make enough copies for all participants, and also for your file.

5. Decide on a deadline by which your demands must be implemented.

6. Select an articulate, self-confident spokesperson for the group who will make the actual formal presentation of your demands, with others making informal presentations.

7. Rehearse your presentations ahead of time, with other group members critiquing your presentation for:

   a. clarity
   b. conciseness
   c. documentation
   d. articulation
   e. persuasiveness

8. Try to anticipate arguments which will be brought up by the other side, and prepare and rehearse appropriate responses, giving appropriate documentation, legal back up for your demands. You need to be thoroughly familiar with P.L.94-142, and Section 504 to use as legal communication.

9. Decide which of your demands absolutely must be met, and which you are willing to postphone to a later time.

AT THE NEGOTIATING MEETING:

1. Go together as a group. As soon as you arrive, introduce yourselves one by one to all your opponents.

2. Take the initiative - you are conveying the message that you are in control.

3. Before you sit down, carefully survey all persons in the room. Identify the most powerful person in the room - and sit down right next to that person - or as closely as possible, if seats next to him/her are taken. Have members of your group do the same. This maneuver will establish your personal equality and the equality of your group with this powerful person.

4. As you are sitting down, put all of your "props" on display, on the table. Your "props" are copies of P.L.94-142, Section 504, Federal and State Rules and Regulations - and other appropriate federal and state statutes. Be sure there are ample markers so you will be able to locate specific references you might need in an instant.

5. After you sit down, pass a legal size pad around on which you have written the following headings:

NAME	DEPARTMENT	POSITION	PHONE

Put your name at the top. Then pass it to the person next to you, making sure that everyone signs in order. By doing this, you will:

   a. have a list of all participants
   b. know from the order of names, who is who, and you will be able to verbally address everyone by name during the meeting.

6. Bring a tape recorder. Do not ask for permission to use it (remember, when you ask for permission, you are giving them the option of saying "no".) Simply sit it on the table and turn it on.

7. If there are comments about the tape recorder, simply make casual comments like: "This is an important meeting, and the modern way to keep a record of a business meeting is to use a tape recorder. "Did you bring one? Well, then, I'll be happy to send you a transcript..." or, "After ...years, my shorthand is so rusty, I have to use a tape recorder for ALL my meetings..." or, if there are any objections:"If you object to my using a tape recorder, why don't we use yours. I have no objections. But, of course, I'd like a transcript..."

AFTER THE MEETING:

1. Immediately confirm in writing - by registered mail - all promises and committments made by officials.

2. Follow up by phone, additional personal contacts, and negotiating meetings to make sure all promises are implemented.

3. Take appropriate action - filing complaints with BEH, OCR, demonstrations, etc - if promises are not kept (See HOW TO ORGANIZE AN EFFECTIVE PARENT/ADVOCACY GROUP AND MOVE BUREAUCRACIES, published by CCHC.)

30
How To Assert Yourself With The Politicians

" I don't bother with politics. Those politicians are either crooks, power hungry, egomaniacs - or all three. And I don't want to get mixed up with them."

THERE MAY BE SOME crooks, egomaniacs, etc., who are politicians, but what they do or don't do will effect your handicapped child. And if you don't let your politicians know what your child needs - they may pass laws that will hurt your child, or fail to vote for laws that could help him/her out of ignorance or because of misinformation.

POLITICIANS IN THE STATE LEGISLATURE AND IN CONGRESS RELY ON THEIR CONSTITUENTS TO INFORM THEM OF WHAT THEIR NEEDS ARE. THEY RELY ON PARENTS TO INFORM THEM WHAT SERVICES ARE NEEDED FOR HANDICAPPED CHILDREN, AND WHAT LAWS ARE NEEDED TO BRING THEM ABOUT.

Don't let your State legislators and Congressmen/women decide your child's fate without your participation. Don't abdicate the right to assert yourself with your politicians. Request those services your child needs which are not yet required by law.

1. Get acquainted with your legislators and congressmen/women. Let them know you are a parent of a handicapped child, and introduce them to other parents in the district. Get together with them just before the legislature goes into session (in Sept. or Oct.) and present them with a written statement of the needs of handicapped children in their district which are not now being met by law. Try to find out approximately how many children are involved and include these statistics in your statement.

2. You might (with the help of appropriate parent groups) conduct a community survey to determine what the community needs are and include the results of your survey in the statement.

3. Report the results of your survey to the press - along with an article about the politician's promise to introduce legislation to effect necessary changes.

4. Make personal visits to your legislators' while the legislature is in session, and ask for their support of specific legislation for the handicapped. Keep in touch with them by letter and telegram -

when crucial bills that will effect your child are up for a vote. Let them know where you stand and how you want them to vote.

5. Join your parent group's campaigns- see National Parent Organization, (Appendix)

6. Put your politicians on your Parent Group Mailing list. This will help them to be informed.

7. Make your politician accountable . Report the vote tally of your politicians in your Parent Group Newsletter. Make sure the politicians each get a copy.

YOUR POLITICIANS CAN ALSO HELP YOU:

1. Put pressure on school officials and other bureaucrats to cut the red tape preventing your child from receiving services he/she is entitled to.

   a. write them a letter when you run across red tape. Send copies to all bureaucrats involved in the red tape.

   b. follow up with a phone call and explain the urgency of the situation and why help is necessary.

Make sure you specifically indicate in both your letter and your phone call which agencies are involved in the red tape, which individuals you have contacted, their responses, etc (you should have this information well documented in your notebook). Ask them again to call the agencies involved. A phone call or letter from state legislators and congressmen/women (or their assistants) will probably make enough of an impression on the offending bureaucracies to get the ball rolling.

WHEN POLITICIANS RENEGE ON THEIR PROMISES - Let the whole world know.

1. Prepare a statement which incorporates their campaign promises (using direct quotes). Opposite each statement, report how the politician has not kept his promises.

2. Send a copy of the statement to the press - with appropriate remarks from you and your group.

3. Write letters to the Editor about the unfulfilled promises .

Following is a letter to the Editor written by the Coordinating Council for Handicapped Children to a Chicago Metropolitan Newspaper - about a former governor's unfulfilled campaign promise. The letter resulted in a request by the Governor for a meeting with CCHC and other organizations involved in the fight to stop mental health cuts. A MAJOR LOBBYING CAMPAIGN TO RESTORE THE CUTS RESULTED IN $5 MILLION RESTORED TO THE DEPT OF MENTAL HEALTH BUDGET, AND AN ADDITIONAL $19 MILLION ADDED AT THE REQUEST OF CCHC AND OTHER PARTICIPATING ORGANIZATIONS. A 500% VICTORY!

Letters: 'Walker's cruel double-cross'

When candidate Dan Walker was running for governor, he attacked Gov. Ogilvie's mental health program as "inadequate," and he promised to improve services for the disabled and the mentally ill. He promised to do so by decreasing the number of middle-management workers in the Department of Mental Health and increasing the number of direct care workers.

Mrs. Des Jardines

Gov. Walker is "keeping those promises" by making the following cuts in mental health services (figures from the Department of Mental Health):

- $4.5 million in cuts in the 1974 mental health budget.
- A phase-out of educational programs for emotionally disturbed children at Chicago-Read Mental Health Center and John J. Madden Zone Center.
- Elimination of mental health program for deaf adults at the Illinois State Psychiatric Institute.
- Cutbacks of 180 staff positions at Dixon State School for the retarded, 101 staff positions from Lincoln State School for the retarded, 85 staff positions at Elgin State Hospital, 181 staff positions at Chicago Read Mental Health Center, 48 positions at Madden Zone Center, 95 staff positions at Tinley Park Mental Health Center, 21 staff positions at Manteno State Hospital, and 90 staff positions at Kankakee State Hospital.

Gov. Walker did not specify in his directive ordering the above cuts which positions were to be eliminated. Therefore, as usual, it is not the administrators who are being fired, but the direct-care personnel. Chicago-area administrative offices at 232 E. Ohio have actually added two additional administrators.

Parents, relatives and friends of the disabled and mentally ill have long memories. They remembered Gov. Ogilvie's mental health cuts in 1970 and supported Walker in large numbers because of his promises.

They will long remember Gov. Walker's cuts in mental health services, special educational services, Department of Children and Family services, and other services to the needy. They will long remember one of the most cruel double-crosses in political history.

CHARLOTTE DES JARDINES
Co-ordinator, Chicago Co-ordinating
Council for Handicapped Children

Chicago

31
How To Stack Public Hearings To Win Your Battles

"I have tried everything I know of to get services for my child, but nothing seems to help".

HAVE YOU TRIED A PUBLIC HEARING?

Most public agencies have public hearings on policy issues, budget issues, legislative issues - and these present an unusual opportunity for parents to assert themselves and make public officials accountable.

FIND OUT ABOUT PUBLIC HEARINGS BEING HELD BY YOUR:

1. local Board of Education
2. state Board of Education
3. local Department of Mental Health and Developmental Disabilities
4. state Legislature
5. Congress
6. local Health Systems Agency
7. Regional Office of the Bureau of Education for the Handicapped
8. Regional Office of the U. S. Office of Civil Rights
9. Other appropriate local, state, and federal agencies
10. local Protection and Advocacy System

Ask the organizations listed above to: place your name on the agenda to present testimony.

PREPARE A WRITTEN STATEMENT (FROM 2 to 5 MINUTES, DEPENDING ON THE AMOUNT OF TIME ALLOTED TO YOU), WHICH WILL BE DIRECT, SPECIFIC, FACTUAL - AND WITHOUT PERSONAL ANIMOSITY.

1. make at least 100 copies - and send copies of your statement to the press - with a brief handwritten note stating "this is the statement. I will be delivering on (date of public hearing) _____ at the _____name of the meeting.

2. ask as many parent organizations and individual parents as you know to do all the above - with organizations preparing general statements and parents preparing more personal statements.

3. contact everyone a day or two before the hearing to remind them. Keep count of how many will be testifying.

4. contact the press the day before the hearing. Ask if they will be covering the hearing, if they would like an interview, etc...

5. bring at least 100 copies of your statement with you to the hearing for distribution to members of the hearing panel, the press, representatives of other organizations who will be there, and members of the general public.

6. Follow the steps outlined in Chapter 7, HOW TO GET RID OF THE SHAKES AND PUT PUNCH IN YOUR SPEECHES.

7. Follow steps outlined in Chapter 32, HOW THE PRESS CAN HELP YOU GET SERVICES .

8. Introduce yourself and members of your organization to other organizations at the hearing who appear to support your goals. Ask them to get involved in your group. Get their names, addresses and phone numbers. Invite them to your next meeting.

FOLLOW-UP

1. Contact the agencies who sponsored the hearing within 5 days of your presentation, and ask when your recommendations will be implemented.

2. Set up a meeting with appropriate officials to plan a course of action.

3. Follow all steps outlined in Chapter 29, HOW TO NEGOTIATE WITH BUREAUCRACIES.

Following is a reprint of a statement delivered by CCHC at a 1978 Public Hearing of the Illinois Department of Mental Health and Developmental Disabilities:

"We are here this evening to speak out and advocate for those too helpless to speak out and advocate for themselves - the mentally ill, and the emotionally disturbed children of Illinois.

"We are here to protest again, the DMH/DD's total disregard for the needs and safety of the emotionally impaired children still remaining in the Tinley Park Mental Health Center's General Children Program.

"We are here because the public agency specifically paid by us, the citizens of Illinois, to help mentally ill children, to shelter them, to provide treatment and therapy for them, has not fulfilled its responsibility.

"The Department of Mental Health and Developmental Disabilities has indicated time and time again that its goal is not to provide services, but to add to the state surplus at the expense of the mentally ill of Illinois.

" An outstanding need in Illinois is residential treatment services for mentally ill children. Yet the FY 79 DMH/DD budget shows $13.5 millions for private residential services for the Developmentally Disabled, and only $636,000 for private residential (purchase of care) services for mentally ill children.

" Why 20 times the amount of money for DD services than for MI - when the DMH/DD 5-year Plan shows that there are an estimated 3% of the child population (and 2% of the adult population) who are mentally ill and in need of services for mentally ill children vs. only 1.65% DD in need of services?

" Why this lack of committment from DMH/DD to mentally ill children?

" We also need to ask - what is happening to the thousands of MI children who need residential services? A few dozen are in good state programs - such as the soon to be dismantled General Children's program and the Adler Center Program. But many more are in unsafe state institutions such as Chicago Read Mental Health Center, whose unsafe conditions have been documented by the Joint Commission on Accreditation of Hospitals and the Illinois Department of Public Health.

" WE NEED TO ASK - AND TO KNOW - what is happening to the children now in the General Children's Program? Where are they to go? We hear talk of Pritzker as a possible facility. But we need to know: what specific plans is DMH/DD making for the use of the Pritzker site as a new location for the General Children's Program.

" WE NEED TO KNOW: How many children from the GCP are being transferred out of state. We know of one who has already been transferred to Texas - after great anguish and great frustration on the part of his parents. The anguish and the frustration is still going on - as the DMH/DD quibbles over the rate the new program will be paid. Will it be $49 a day - or $66 a day?

" DMH/DD is always lamenting its practice of out of state institutionalization of MI children. "There is no place else for them to go," they keep insisting. WE SERIOUSLY QUESTION THIS, when several facilities now providing day services to MI children have informed us that they have applied to DMH/DD to provide residential services but have been denied state funds to do so.

" WE ALSO NEED TO KNOW: Why hundreds of parents of mentally ill children are still being forced by DMH/DD and Dept. of Children and Family Services , to give up custody of their own children - and go through the humiliating process of declaring themselves unfit parents in court, in order to get help for their mentally ill children. THIS IS A HUMILIATION WHICH IS NOT REQUIRED OF PARENTS OF DD CHILDREN. IT IS REQUIRED ONLY OF PARENTS OF MI CHILDREN.

" In closing, we want to reiterate: we are still waiting for the day when DMH/DD willingly and financially accepts its responsibilities to provide services for mentally ill children of Illinois.

32
How The Press Can Help You Get Services

"I've tried everything to get services for my child. Nothing has worked so far..."

When all else fails, it's time to go the newspapers and the television stations. And the radio stations. And the magazines. And every other part of the press.

Newspaper reporters and columnists, television and radio newscasters, are often interested in "human interest" stories. And your story about all the run arounds you have been through, trying to get services for your handicapped child may be of interest to them.

To Get The Press Involved, Do The Following:

1. Put the problem in writing, documenting everything, with dates, places, names and bureaucracies involved, individuals involved, their response or lack of response, and the number of times you have contacted everyone. Start the letter with an attention grabbing statement. Try to convey the urgency involved.

2. Let them know how much this means to you; how your family is effected by the problem. Write with emotion, but don't let the emotion run away and get out of control.

3. Stay away from personal attacks. Simply state the facts and let the facts speak for themselves (their message will be dramatic enough). Tell them you are available for an interview to discuss the problem further.

Send The Letter To:

1. Columnists of newspapers, whose columns indicate human interest.

2. City editors of your local newspapers

3. Television and radio commentators whose commentaries indicate an interest in special stories.

4. Send copies of your letters to all bureaucrats who have been giving you the run-around.

Approximately 5 days after you have sent your letters, call each columnist and commentator and find out if they are interested in your story.

Also, WRITE LETTERS TO THE EDITOR, using an abbreviated version of the letter described above - try to limit it to one page). Simply address it to: Letters To The Editor - _____Newspaper name and address. Send copies of your Letter To The Editor to the bureaucrats involved. The bureaucrats causing the delay will want to look like "good guys" when the press calls and you will probably get all kinds of action very shortly.

The following clippings tell the story of a parent who succeeded in single handedly moving one of Chicago's most stagnant bureaucracies - The Chicago Transit Authority - by following the steps outlined in this chapter.

Following the Coordinating Council's instructions, the parent began by "going through channels":

1. Contacting the Public Relations Department and asking for a special permit to allow the use of her physically handicapped child's stroller on the bus (she was told this was against CTA policy).

2. Contacting the CTA President and asking him for a special permit - when the Public Relations Department turned down her request.

3. Contacting the Mayor's Office when the CTA President refused her request.

Only when all available channels had refused to respond, did the parent contact the press - with remarkable results!

CHICAGO SUN-TIMES, Thurs., Jan. 22, 1975

They won't let her crippled child ride bus

Bob Greene

Further heartwarming tales of sweet Chicago, the city that works:

Mrs. Lorraine Alavi is trying to help her daughter get well. The little girl, Linda, is 2½ years old and was born with cerebral palsy. Mrs. Alavi, whose husband works as a busboy, does not have much money. But the doctors at Children's Memorial Hospital are treating Linda at a reduced rate.

To take Linda the more than four miles to the hospital for the regular therapy sessions, though, Mrs. Alavi must rely on the buses of the Chicago Transit Authority. She cannot afford cabs. Linda, because of the crippling disease, cannot stand, sit erect, hold up her head, walk or crawl; the little girl must be transported to the hospital in a stroller.

"I have a 1-year-old daughter, too, who is healthy," Mrs. Alavi said. "We don't have the money to pay for a baby-sitter, so when I take Linda to the hospital I have to carry the younger baby on my back, in a carrier. I put Linda in an umbrella stroller—it's the smallest stroller you can buy. But five times recently, CTA bus drivers have told me that I'd have to take the stroller off the bus and have threatened to throw me off even after I told them Linda has cerebral palsy."

Several of the drivers told Mrs. Alavi to take Linda out of the stroller and "have her stand up for the ride." When Mrs. Alavi said that the child was not able to stand, the drivers said that they could not help that — and that regulations were regulations, no strollers allowed on the bus. One driver, Mrs. Alavi said, raised his voice and said if he ever saw her and Linda on the route again, he would refuse to pick them up. Mrs. Alavi always managed to stay on until she got to the hospital, but the drivers told her they would not allow her to continue to do this.

Mrs. Alavi was upset, but she thought that if someone in authority were told about Linda's disability, perhaps an exception could be made. She called the Co-ordinating Council for Handicapped Children. The council suggested she call the public relations department of the CTA.

She did. The public relations department said that if Linda's stroller caused another passenger to trip and become injured, the CTA would be at fault and nothing could be done. Mrs. Alavi asked if perhaps Mayor Daley's office could help and the public relations people said that might be a good idea.

Mrs. Alavi called the Mayor's Office of Inquiry and Information. She was told that the CTA governs itself and is outside of Mayor Daley's bailiwick. Mrs. Alavi had a little trouble with that one, but she decided to call the CTA again.

She called the office of Milton Pikarsky, the chairman of the CTA. Pikarsky, who is in the midst of the transition to his new job as the $82,500-a-year chairman of the Regional Transportation Authority, was too busy to talk. Mrs. Alavi was switched to Dennis Murphy, of the CTA's customer service department.

Murphy told Mrs. Alavi strollers were not allowed on board CTA buses. Mrs. Alavi said she understood this and explained about Linda's cerebral palsy and the hospital visits. Murphy said enforcement of the stroller regulations was up to the individual drivers. Mrs. Alavi asked Murphy if he could send her a short note, explaining that they had talked, so she could show it to bus drivers. Murphy said that would be "impossible."

(continued on the next page)

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CTA ban

With 1-year-old Brenda strapped to her back, Mrs. Lorraine Alavi tries to get Linda, 2, aboard bus at Ardmore and Sheridan. Linda, who can't walk because of cerebral palsy, has been banned by CTA bus drivers, who say regulations forbid strollers. (Sun-Times Photo by Jack Lenahan)

This week, Mrs. Alavi canceled Linda's regular appointment at Children's Hospital, to avoid the threats of eviction from the CTA drivers. When the social workers at Children's learned of Mrs. Alavi's problem several weeks ago, they gave her some money for a cab, but Mrs. Alavi was embarrassed by that and did not want to impose on the social workers again.

"I just don't know what to do now," Mrs. Alavi said. "I'm totally dependent on the CTA. If Linda's ever going to get better, she has to go to Children's Hospital for her regular therapy. The doctors can't say if the treatment will work or if it won't work — it's a gamble. But it's the only hope we have. During the first year of Linda's life, she was at the hospital 43 times. At first she couldn't put her hands together. Now she can do that. If I stick my finger in her hand, she can squeeze the finger now. It doesn't sound like much, but you don't know what it means to us.

"Recently, the doctors have been talking about helping Linda to raise her head. But now I can't get to the hospital. Often I would wait for an uncrowded CTA bus to come, so that I wouldn't be inconveniencing any of the passengers. But one of the buses was almost empty, and that driver was the meanest in telling me that I wasn't allowed on with the stroller."

On Wednesday, I called Dennis Murphy at the CTA office and told him that I had talked with Mrs. Alavi. Murphy read to me from the CTA regulations and told me that any object that was "likely to cause an accident, soil clothing or injure passengers" was not allowed on a CTA bus—and that the stroller used to take Linda Alavi to the hospital fit into that category.

I asked him if he could write the letter Mrs. Alavi had requested so she could have something to show to the drivers. "No, sir," Murphy said. "We can give her no letter, and we can give her no assurance of a ride every time she wants to get on. We would be liable for any injury caused by that stroller."

Mrs. Alavi said she does not know where to turn now. "All I ask for is a chance to give my daughter to walk someday, and to sit up by herself. Now I'm being told that I can't even take her to the hospital. I know that this is a small problem in a city as big as this, but it's my whole world."

CTA promises bus rides for crippled child

By Roger Flaherty

CTA spokesmen said Thursday that they are taking action to ensure that Mrs. Lorraine Alavi encounters no further difficulty with bus drivers who seek to bar the stroller she uses for her handicapped daughter.

Mrs. Alavi's clashes with bus drivers and the CTA bureaucracy were described by Sun-Times columnist Bob Greene in Thursday editions. Her daughter, Linda, 2½, is a cerebral palsy victim and cannot stand, sit erect, hold up her head or crawl.

Mrs. Alavi has been using a stroller to take her to and from Children's Memorial Hospital for therapy sessions. She carries her daughter, Brenda, in a shoulder harness. Five times in recent weeks, bus drivers have threatened to throw her off the bus, she said, because CTA rules forbid strollers.

When she called the CTA to ask for assistance, spokesmen there repeated the rules and said she would have to follow them.

By late Thursday afternoon, the CTA attitude had softened, however. A spokesman said the CTA would make sure that Mrs. Alavi and Linda had no further trouble on the bus.

"We are deeply concerned about the needs of the handicapped and are pushing forward to provide improved service for any and all such persons," the spokesman said. "In the interim, we encourage those who do encounter difficulties with CTA personnel to report their concern directly to the CTA public affairs department."

Greene's column provoked an angry response from readers over the CTA's unbending stance on use of the stroller, and calls poured into the Sun-Times, the CTA and United Cerebral Palsy of Greater Chicago. Many offered rides or cab fares to help Mrs. Alavi out.

Pikarsky bends the rules. See Kup, Page 84.

All the offers of aid were turned over to Mrs. Alavi.

Edward Blumberg, who owns his own taxi, offered to drive her to and from Children's Memorial Hospital "anytime she wants to go." Blumberg, who said he has a son who suffers from cerebral palsy, said he would not charge for the service.

"I don't think the CTA treated her right," he said. "That's a hell of a lot of nerve."

Another caller, a woman who asked not to be identified, said she called the CTA to express her outrage over the incident. She called the drivers' attitude a "dirty, rotten thing."

Yet another caller offered to donate a bicycle with a carriage to Mrs. Alavi.

Roger Olsen, associate executive director of United Cerebral Palsy, said his agency has contacted Children's Memorial and offered to provide help. Olsen noted that Mrs. Alavi had received counseling from the agency a little more than a year ago on how to deal with the problems of a handicapped child.

"She seemed to be satisfied with our service then," he said.

Olsen said the agency provides bus service for 150 children and young adults who attend a special school, and that occasional "escort" service is provided for hospital or clinic care. He said Mrs. Alavi would be assisted by the agency if she seeks its help.

He said the switchboard had been going constantly Thursday morning with inquiries from readers of Greene's column as to what services were available.

One person who seemed upset about the column was Dennis Murphy, an employe in the CTA customer service department, whose refusal to seek an exemption for Mrs. Alavi was noted by Greene.

Asked if he had received many calls, Murphy said in ironic tones: "Yes, a few." He then said any more comment would have to come from the CTA public relations department.

One caller to The Sun-Times, a woman who said she is the mother of a cerebral palsy victim, was sympathetic to Murphy and the CTA. "You have to think in terms of the safety factor — both to Mrs. Alavi and her children and other passengers," the woman said.

KUPCINET

Kup's column

Milton Pikarsky, outgoing chairman of the CTA, reacted immediately when we called his attention to Sun-Times columnist Bob Greene's story about Mrs. Lorraine Alavi and her 2½-year-old cerebral palsied daughter, Linda. Mrs. Alavi's only means of transportation with Linda to Children's Memorial Hospital, where the child undergoes therapy sessions, is the bus. And bus drivers give Mrs. Alavi a hard time because Linda has to be transported in a stroller, which is prohibited by CTA regulations. Pikarsky's response was immediate: "We are a public service agency and we should relax the rules under certain conditions to help the public. This certainly is one of those conditions. Tell Mrs. Alavi an order will go out to bus drivers to accommodate her." . . .

33
Others Who Are Winning By Being Assertive

ASSERTIVENESS IS NOT A NEW CONCEPT. PEOPLE AND ORGANIZATIONS HAVE WON THEIR OBJECTIVES THROUGH ASSERTIVENESS TECHNIQUES FOR THOUSANDS OF YEARS.

ALL AROUND YOU ARE EXAMPLES OF INDIVIDUALS AND ORGANIZATIONS WHO HAVE "WON" AND REACHED THEIR GOALS - BY BEING ASSERTIVE. FOR EXAMPLE:

The Thirteen Colonies
Teachers
Nations
Trade Associations
Professional Associations, such as A.M.A. (American Medical Assn.)
A.B.A. (American Bar Assn.)
U.S. Chamber of Commerce
Student Associations
Parent Group and Coalitions
Political Parties
Government Agencies
Consumer Groups
Pressure Groups

THERE ARE ALSO MANY INDIVIDUAL EXAMPLES: HERE ARE JUST A FEW (listed alphabetically)

Susan B. Anthony - whose persistence in the long struggle for female suffrage won American women the right to vote in 1919.

Joan of Arc - whose courageous assertiveness inspired a defeated French Army to victory.

Jane Byrne - (Chicago's Mayor) whose outspoken assertiveness got her fired from her job in City Hall - but a year later, got her elected the head of City Hall.

Queen Esther- whose courageous assertiveness saved her people from destruction at the hands of a cruel politician.

Betty Friedan - whose 1963 book the Feminine Mystique launched the Women's Liberation Movement.

Patrick Henry - His assertive "Give me Liberty or Give me Death" became the cry of the American Revolution.

Abraham Lincoln - whose assertive refusal to allow the south to secede from the Union led to the Civil War and the Emancipation of American Black slaves.

Martin Luther King, Jr. - whose non-violent assertiveness inspired millions of American people.

Martin Luther - whose assertiveness against church corruption sowed the seeds which resulted in a new Church.

Moses - whose assertiveness in insisting, persisting, and persevering - convinced the Pharoah to finally "let his people go".

Ralph Nader - who has organized the strongest consumer movement in the nation. Who has succeeded in making our politicians and our manufacturers accountable.

Florence Nightingale - whose persistent assertiveness against British Bureaucracies was responsible for professionalizing nursing.

Rosa Parks - whose assertive refusal to give up her seat on a Montgomery, Ala. bus in 1954 sparked the citywide bus boycott - which propelled Martin Luther King, and the Southern Leadership Conference to national action and prominence.

St. Bernadette Soubiroux - whose quiet and persistent assertiveness won over her detractors, who eventually proclaimed her a saint.

Phyllis Schlafley - whose persistent assertion through lobbying halted passage of the ERA (Equal Rights Amendment).

President Harry Truman - whose gutsy assertiveness got him the nickname "Give 'Em Hell Harry", and won him a presidential election many had predicted he would lose.

Can you think of other assertive men or women you have met - in your Bible, in your history books, or in your newspaper?

You will find that the people who stand out as DOERS and MOVERS and ACHIEVERS are all assertive people, although their assertive styles may differ.

34
What If I Fail?

IF YOU LEARN FROM YOUR FAILURES, THEY ARE NOT FAILURES - BUT SIMPLY PART OF THE FOUNDATION OF YOUR NEXT SUCCESS

Your failures can be the seeds from which your next success will grow.

WHEN YOU FAIL:

1. Analyze the reason for the failure.

   a. on a long sheet, make three columns. In the first column, list all the things you did wrong.

   b. in the second column, list all the things you did right.

   c. in the third column, list all the things you can do to turn wrongs into rights.

   d. Rehearse right behavior, right responses - until they become part of your natural repertoire.

Go the extra mile to turn your failures into successes. Make a list of:

1. All the times an assertive response has produced results

2. How you could have made your demands more effectively, with better results.

3. What you could have said better ... how..."if only I had done..." "If only I had said..."

Make a list of all those "if only's" on one side of the page - with an appropriate response; action you wish you would have done. How would you have done things differently?

Picture yourself in a situation when you really did something well. What was it about the incident that made it a positive one? How can you utilize some of the positive things you did in that incident into future situations that will turn them into successes?

Visualize yourself in a situation where you are successfully utilizing assertiveness techniques described in this book: VISUALIZE YOURSELF AS WINNING AND GETTING WHAT YOU WANT - AT IEP MEETINGS, AT STAFFINGS, ETC. START THINKING OF YOURSELF AND TREATING YOURSELF AS A SUCCESS. AND YOU SOON WILL BE ONE!

PART VI

ASSERTIVENESS SUCCESS STORIES

How I Grew From A Timid, Frustrated, Helpless Lady To An Assertive Parent

by Bobbie Teplitz

For years I had been a "nice, quiet, friendly lady. But really, I was nice, timid, frustrated, angry and afraid to say anything. When I was a child, in school, I was the one who was always absent on days oral reports were to be given. I was the one crunched down in the seat, so no one would call on me: and, if I was called on, would just about die.

The change in me started after one of my children was diagnosed as having learning disabilities, and my husband and I began having problems getting services for him. In the beginning, I was timid and accepted what we were being told as the truth. I was extremely nervous when dealing with administrators, because I was made to feel like an over anxious mother who didn't know as much as they did; told not to worry, told that, of course they knew best. I was given the usual run around.

After this had gone on for a while, I felt like I could take it no longer. I just had to do something. I then became aggressive, angry, frustrated and maybe "not so nice" when I realized school officials were just putting me off, not really helping my child and just trying to pacify me. When the needs of our child required that we take immediate action, I became a "not so nice" angry, frustrated aggressive lady. At least, then, I would be heard.

When I realized that anger still was not getting the results I wanted, I began directing my anger towards my goal. I began to inform myself and become knowledgeable. As I became more knowledgeable, I gained confidence. After having been through a due process hearing and appeal, having actively participated in workshops, discussions, and public hearings (things which a couple of years ago I wouldn't even have thought of doing), I am now much more confident. In many cases, I am much more knowledgeable than those who, in the past, had intimidated me.

Now, when I call, I no longer apologize for "bothering" officials. In most cases I speak to them right away, or my call is immediately returned. I am no longer put off. I am getting my rights by being an assertive parent.

ASSERTIVENESS HAS ALSO HELPED OTHER PARENTS and other handicapped children.

I am now helping other parents obtain services and teaching them to be assertive as a volunteer for the Coordinating Council for Handicapped Children. In less than a year I have changed from a timid, intimidated, frustrated and helpless parent - into an assertive parent who gets things done and is teaching others how to do likewise.

How I Asserted Myself At My Child's IEP Meeting

by Cindy Grass

Year after year, my daughter's home school district had refused to pay for a summer program for her. When I would call the district superintendant, I was told that he could not talk to me, and that there was absolutely no money available for my daughter's summer school program, that there was no money to provide summer school for anyone.

My daughter, Dawn, is 13, and is deaf and autistic. She needed a summer program to prevent regression. I DECIDED THIS YEAR WOULD BE DIFFERENT. I WOULD FIGHT. I WOULD BE HEARD - not only by the superintendent but by the school board as well. I knew that other parents had been successful in convincing their districts to pay for summer school.

In the past, I had found it difficult to express myself in groups larger than 3. Over the years, I have gradually learned to put aside much of my shyness while working to obtain better services for Dawn. I felt ready for the test of face-to-face confrontation. I had decided that if I didn't win the first battle, I would file for a Due Process Hearing (which would cost my district thousands of dollars), and file a complaint with the U. S. Office of Civil Rights.(Department of Health, Education, and Welfare)

In early Spring, 1979, the school psychologist, and teacher verbally recommended at an informal conference with me, that Dawn attend summer school. I asked that the IEP (Individualized Education Program) be amended immediately to include that recommendation. I knew that the school district was bound to deliver services written in the IEP, and that the IEP was to be based on my child's needs.

I was assured that the summer school recommendation would be included in the IEP in the upcoming Annual Review conference. I accepted this, still unaware of the politics of the situation.

In the meantime, I attended,with my daughter, the school board meeting where summer program tuition would be discussed. At the meeting, the superintendant recommended against approval of two requests for summer school, stating there would be additional requests for summer school if these were accepted.

I interrupted and asked to read a brief statement. I passed out copies to the Superintendent, Board, and the three members of the audience. I also provided them with a copy of the State Education Office - Educational Rights Handbook that I had obtained from the Coordinating Council for Handicapped Children.

I stated that P.L.94-142 required that special education services meet the unique needs of my child and that, due to the nature and severity of her handicaps, she would regress without summer school. The Board postponed its decision until the next Board meeting. A few days later, an article was printed in the newspaper about the meeting.

My daughter's Annual Review was scheduled for a week later. Last years' Annual Review had been attended by myself, the teacher, and the district psychologist. In preparation for this year's meeting, I wrote a Parent Input Statement outlining what I felt Dawn needed. I also asked another parent to go with me (I had attended her Annual Review previously) and an advocate. I brought my tape recorder. I dressed in a business suit, visually establishing myself as an equal partner with the professionals.

This year's meeting was attended by 10 school district representatives: a high incidence special education cooperative director, and its psychologist, the district superintendent, the local public school principal, and its psychologist, the program supervisor, the program psychologist, the vocational education coordinator, the speech therapist, and the teacher.

The three of us took the initiative and introduced ourselves. I set up the tape recorder and passed around a sign-in sheet, so I would have the names of those in attendance in front of me.

The atmosphere was tense, but matters proceeded normally. After the teacher finished explaining the IEP, I passed out my Parent Input Statement. Those present glanced at my statement. The supervisor said that she was sure that I was in agreement with Dawn's Annual Goals, and she asked me to sign the Annual Review Form.

Summer School had not been included in the IEP, nor had it been mentioned verbally. I asserted that I wanted the recommendation for summer school written in the IEP. The supervisor said she could not put it in without district approval. The district superintendent immediately said no. I asked him to repeat what he said into the tape recorder. He refused, and denied saying no. I replayed the tape to confirm that he had said no. I was obviously angry at this point.

I insisted that the summer school recommendation be written in the IEP. Finally, the supervisor agreed to write on the Annual Review Form that summer school was recommended, pending Board approval.

The principal of the local school district suddenly burst out demanding that I retract the newspaper article about an earlier school board meeting. I informed him that I had not written it, and that we were not here to discuss the article.

Although I had won a partial victory by getting the recommendation for summer school in writing, I had let the school district representatives throw me into a defensive position by becoming angry, and insisting that the superintendent repeat his denial of summer school into the tape recorder. The focus of the meeting had changed from Dawn's needs and what the law required, to open hostility. Recognizing this, I requested another meeting. I refused to wait for a Board decision to be conveyed by phone or mail.

I walked away amazed and angry that 10 school officials had attended Dawn's Annual Review. I was angry that the district could afford to have 3 psychologists at this meeting - 2 of whom had never even seen Dawn - and yet claiming they could not afford summer school. Most of the people had attended this conference, not to give input about Dawn's unique needs, but to see that the district's priorities would not be challenged.

I BEGAN TO PLAN FOR THE NEXT MEETING IMMEDIATELY. I made up my mind to bring 10 people with me the next time. I would not only pass out the Parent Input Statement, but would read it aloud to insure that my concerns would be heard. I brought refreshments to provide an informal atmosphere, and of course I brought my tape recorder.

I was able to recruit 8 people to attend the meeting with me. (I asked the men to wear suits so that they would look official) As we entered, a look of surprise came across the school officials' faces. Luckily, they had chosen a fairly large room for this meeting. Nine representatives from the school district were present.

The meeting proceeded as before. Summer school was not mentioned until I read my Parent Input Statement. A discussion of my statement followed, but the summer school issue was avoided. When the Assistant Director attempted to end the meeting, I again asserted that I wanted the summer school recommendation written into the IEP.

The Assistant Director said he couldn't write it in without district approval. I asserted that the IEP was to be based on Dawn's needs and that the summer school was necessary to meet her needs. I made it clear that if he refused to write it in the IEP I would have grounds for a Due Process Hearing, and I intended to file for one.

At this point the District position began to change. The superintendent stated that it would be possible to consider Dawn's case on an individual basis. The summer school recommendation was written into the IEP, and a week later the School Board formally approved payment of the tuition.

How I Won More SSI Benefits For My Brother

by Darline Handley

I fought my local Social Security Office for 2 years, trying to get the full amount of SSI (Supplemental Security Income) benefits for my 37-year old physically handicapped brother, who shares a home with my mother.

On November 15, 1979 the Administrative Law Judge finally ordered a decision in my brother's favor and ruled that:

1. He is entitled to the full amount of SSI benefits allowed for an individual - even though he lives in the same household as my mother.

2. The 1/3 reduction of benefits which Illinois Social Security offices automatically apply in cases of shared households was not applicable in this case.

3. That the full maximum payments will be retroactive to the date of the application

Until I was informed by The Coordinating Council that my brother (and other handicapped adults sharing a household) were entitled to maximum individual benefits, my brother's SSI payments were automatically reduced by 1/3 - simply because he lived with my mother.

The Social Security Administration had automatically assumed (without making any inquiries) that my brother was receiving "support and maintenance" from my mother. Since "support and Maintenance" is considered unearned income, "it was deducted from the SSI payments - as is all income. This is where the 1/3 reduction came from.

This seemed very unfair to me, and with the support of the Coordinating Council, I decided to fight it. I was informed by the Council that:

According to the SSI Claims Manual #12236, persons can qualify for the full amount of monthly benefits (without the 1/3 reduction) when living in another person's household if the SSI recipient meets at least one of the following conditions:

1. Provides evidence of an ownership interest in the home. Ownership may be held individually or jointly.

2. Provides evidence of rental liability for the household.

3. Pays at least his pro-rata share of specified household operating expenses.

4. Does not receive both support and maintenance (food and shelter) from the parent or householder.

Following the Coordinating Council's suggestion, I did the following:

1. Obtain from my mother a notarized statement that:
   a. she is not contributing support and maintenace from her son.
   b. her son is completely self-supporting and is paying his pro-rata share of household expenses.

2. Draft a monthly expense list specifically showing that my brother is paying his pro-rata share of monthly expenses. In a two person household, this means that the monthly expense list showed that my brother is paying:

   . 1/2 the rent or mortgage
   . 1/2 the cost of all utilities
   . 1/2 the cost of all food
   . 1/2 the cost of all other household expenses such as heating, home repairs, remodeling, etc....
   . all his clothing costs
   . all his entertainment costs
   . all his personal maintenance costs such as shaving supplies, etc.

During my two-year struggle, I visited the Social Security Office at least ten times and made more than fifteen phone calls to them. During this time SSI employees continually tried to discourage me, telling me no one else ever tried to get the full amount. After one year, I finally hired an attorney who pleaded the case to the Administrative Law Judge.

MY VICTORY IS A LANDMARK DECISION FOR ILLINOIS SSI CLAIMANTS, AND PERHAPS FOR THE WHOLE NATION AS WELL!

How We Asserted Ourselves With Our Politicians — And Won!

by Mary Cotter, President, Ill. Council for Citizens
with Learning Disabilities

If you've been told: you can't fight City Hall, or politicians won't listen to you, or it's no use taking on the big guys - - pay close attention to the following paragraphs, and find out how persistent, organized efforts paid off.

One of the mandates of the new P.L.94-142 is that handicapped children be integrated into the regular classroom to the degree in which they can function, and be educated with their non-handicapped peers. This is interpreted as "Mainstreaming", and regular classroom teachers are expected to educate these youngsters.

But how effective can a teacher be, who has no knowledge or understanding of the child's handicap? This is especially important in the case of Learning Disabled children, whose perceptual problems are not always obvious, and, according to CLOSER LOOK and CCHC reports, comprise the single largest disability group making inquiries.

Parents of LD youngsters have long felt the need for preparing teachers to recognize these traits, and in 1975, the Illinois Association of Citizens with Learning Disabilities, a volunteer group of parents and professionals, decided to do something about it. An amendment to the School Code was necessary, and the State Legislature had to mandate the teacher training institutions to incorporate an extra course in their curriculum. This course was to require all teachers in Illinois take a survey course in the characteristics of the the exceptional child, including but not limited to, learning disabilities, in order to be granted state certification.

The task seemed insurmountable. Legislators responded indifferently to initial approaches. And colleges and universities balked, saying they had enough mandated programs now: and there was really no need for this new course.

But we were committed, and spared no effort. We contacted the parents in all Learning Disability chapters throughout the state, asking them to write their senators and representatives and inform them of the need for this bill (which became known as HB 150). Other statewide organizations said they would get

behind us - - letters, telegrams and phone calls went to the legislators whenever our bill appeared on the agenda. At one time, our parent group hosted a very successful complimentary brunch in Springfield, in a church hall adjoining the Capitol.

At 11:30 AM no legislator had come, so a few of us went over to the Capitol and sent notes in with a page to remind them (although each legislator had received a personal invitation from his constituent).

At 12:30 over 50 legislators had signed in, visited with parents from their districts, had a delightful lunch, and said they really hadn't understood the problem until our explanation at the brunch.

We continued to inform various groups throughout the state, always reminding them of the need for support, even to passing out stationary, and posting the letters to the legislators ourselves.

When the bill finally passed the House and Senate, the Governor vetoed it. But we refused to accept defeat. That only drove us harder . The override passed unanimously, the Governor signed the bill, and now HB 150 is law in ILLINOIS. AT LAST - SUCCESS!

It took persistence, organization, and cooperation. BUT IT WORKED, and it was worth it all.

PART VII

YOUR RIGHTS

SPECIAL EDUCATION RIGHTS OF HANDICAPPED CHILDREN

For those children, ages 3 through 21, whose differences are so great that they need specially designed instruction, tax supported appropriate education must be provided at no cost to the parents. All such special children are guaranteed free instruction and related services by the Federal Law, PL 94-142, the "Education for All Handicapped Children Act."

NOT ALL THE PROBLEMS THAT PREVENT LEARNING ARE OBVIOUS. An evaluation of your child by the school is necessary to identify the problem or problems, determine appropriate placement, and plan an <u>Individualized Educational Program</u>.

Different types of special education programs are available in public schools to meet the wide range of individual needs.

Your local school district must provide the educational services your handicapped child needs. Special Education Services must be provided for your child if he/she has a problem with:

VISION	BEHAVIOR	RETARDATION	LEARNING DISABILITIES
HEARING	HEALTH	SPEECH	PHYSICAL IMPAIRMENT

THE LEAST RESTRICTIVE ENVIRONMENT (MAINSTREAMING)

Each child must be placed in a program that is as typical as possible, while still meeting his/her educational needs. That way, both "special" and non-handicapped children can learn to understand and respect each other. Special classes and separate schooling must be provided only when the nature or severity of your child's handicap prevents achievement of a satisfactory program in a regular class.

AN INDIVIDUALIZED EDUCATION PROGRAM FOR YOUR HANDICAPPED CHILD (IEP)

Your local school district must develop an INDIVIDUALIZED EDUCATIONAL PROGRAM for your handicapped child-especially designed to meet his/her unique needs.

The IEP must be developed at a special meeting, and must include your participation, and the participation of:

- Your child's teacher
- A representative of the public school, other than your child's teacher, who is qualified to provide or supervise your child's special education program
- Your child, where appropriate
- A member of the evaluation team or staff member who is knowledgeable about the procedures and results of the evaluation (for a newly evaluated child)
- Other persons, of the school's or your choosing, who have a current educational interest in your child

<u>The IEP will consist of</u>:

- A statement of your child's present educational performance level
- Annual goals for your child
- Short term instructional objectives
- Specific educational services your child needs
- Specific related/supportive services, based on determined needs-such as speech therapy, physical therapy
- Projected date of educational and related services and anticipated duration of these services

- The extent, if any, of your child's participation in the regular education program of the school
- Appropriate criteria, evaluation procedures, and the schedules for determining annually (at least) whether instructional objectives have been achieved.

Your child's IEP can be delivered through:

- A regular class in a public school, with appropriate supportive/related services
- A special class in a public school, with appropriate supportive/related services, if necessary
- A special public school
- A special education program in private day or residential school which meets state standards(if this is needed to meet the educational needs of the child)
- A special home or hospital program if your child is absent more than two consecutive weeks due to his handicap
- A special education program in a state residential facility

Appropriate related/supportive services must be provided to meet your child's needs as indicated in his/her IEP. These can be:

- Speech and language services
- Social work services
- Special readers
- Braillists, typists, and interpreters
- Physical and occupational therapy
- Other necessary therapeutic services
- Consultative services
- Supportive institutional services
- Counseling
- Psychological services
- School health nurses
- Parent counseling and training
- Resource centers
- Medical services for evaluation and diagnostic purposes

Your child must receive appropriate non-academic services and extracurricular services, such as:

- Music, Art, and Home economics
- Adaptive Physical education (if unable to participate in regular Physical Education)
- Other non-academic subjects that other children in your school are receiving
- Recreational opportunities that other children in your school are receiving

IF YOUR CHILD CANNOT BE SERVED IN A PUBLIC SCHOOL PROGRAM

If it is determined at the IEP Conference that your child's educational needs cannot be met through a public school special education program, your local school district must provide an alternate placement - in a state operated facility, or in a private school.

Public funds will pay for your child's tuition to a private school if it is determined that the public schools cannot provide an appropriate program for the child.

IF YOUR CHILD'S PRIMARY LANGUAGE IS NOT ENGLISH

If your child's primary language is not English, he/she must be evaluated by a qualified psychologist in the primary language of your home. An interpreter must be provided if such a psychologist is not available. All communications from the school about your child must be done in the primary language of your home.

IF YOUR CHILD ATTENDS A NON-PUBLIC SCHOOL

If your child attends parochial, independent, or other type of private school

and needs special education services, your school district must provide them through special arrangements.

TRANSPORTATION SERVICES

Your school district must provide transportation to and from the school at no charge, if your child's handicap or distance from the school requires it.

IF YOU DISAGREE WITH PLACEMENT-AN IMPARTIAL, DUE PROCESS HEARING

If you disagree with the proposed IEP; if you are dissatisfied with your child's present placement; or if you feel you have been denied any of your rights - you have the right to an IMPARTIAL DUE PROCESS HEARING. An Impartial Due Process Hearing is a special hearing set by the Illinois Office of Education, where an impartial hearing officer hears both sides and renders a decision to the local education agency.

Your request for a hearing must be made in writing to your public school district superintendent. If you wish to challenge the placement of your child, your request for a hearing must be made within 10 school days of your receipt of notification of the proposed placement. Within 5 school days of your request for a hearing, the local school district will schedule a conference to review the case. Your participation and the participation of representatives of your choosing, will be an important part of this conference.

If the controversy cannot be resolved at this conference, a due process hearing will be scheduled. A certified letter requesting the appointment of an impartial hearing officer will be sent immediately to the Illinois Office of Education, with a copy to the parents.

The hearing will be scheduled by the Hearing Officer at a time which is convenient to you and to representatives of your choosing (a lawyer, an advocate, another parent).

Your child will remain in his present program until the hearing has been held and a decision has been rendered.

The state appointed hearing officer's recommendation will be communicated to you in writing, by certified mail within 10 school days after the hearing.

If you are not satisfied with the result of the hearing, you have the right to request a state-level review. You also have the right to appeal to the courts after other levels of appeal and communication have been exhausted.

5 BASIC STEPS FOR SPECIAL EDUCATION SERVICES

1. AWARENESS OF YOUR RIGHTS.

   These are explained in this material which is based on the following materials: P. L. 94-142; School Code of Illinois, Article 14: State Rules and Regulations to Govern the Administration and Operation of Special Education; Family Education Rights and Privacy Act of 1974; Illinois School Records Act; Section 504, Rehabilitation Act of 1973.

2. REGISTRATION FOR SPECIAL EDUCATION.

   If your child is not in school, you must register him/her (as a child needing special education services) at your local public school. You

should take with you a copy of your child's birth certificate. If your child is already in school, you should request an evaluation by talking with your child's teacher, the school social worker, the school principal, or other appropriate personnel.

3. EVALUATION.

You will be notified of the school's decision to evaluate or not to evaluate your child, and the reasons for the decision.
If the school decides to conduct an evaluation, it will be conducted according to the nature of problems causing the referral. An evaluation can be as simple as a speech and language test, or as extensive as a psychosocial study, educational evaluation, a neurological, a speech and hearing assessment, or a complete medical evaluation. Your consent is required before the school can make certain individual evaluations.

4. INDIVIDUAL EDUCATION PROGRAM.

After your child has been evaluated, public school personnel, other involved professionals, and you, the parent, will decide on the special education services appropriate to meet your child's needs. You will be informed before the conference of its time and place. It will be scheduled at a mutually convenient time. Your participation will be an important part of this conference. Interpreters are to be provided if necessary.

5. PLACEMENT.

The school district must make a decision regarding your child's eligibility for special education and the kind of program he needs - within 60 school days of the referral date or date of application for services.

Your child must receive recommended services as soon as possible after his IEP has been developed - but no later than the beginning of the next school semester. If this is not possible, interim services must be provided, and you must receive written notification of such services.

You have the right to object to a proposed placement and to appeal to the State - The Illinois Office of Education - for a review of the placement decision if the case cannot be ressolved at the local level.

NO DISCRIMINATION / NO BARRIER

in Education, Employment, and Service Programs

(Summary of Section 504, Rehabilitation Act of 1973 - P.L. 93-112)

SECTION 504 has been called "the FIRST FEDERAL CIVIL RIGHTS LAW protecting the Rights of the Handicapped". It provides that: "no...qualified handicapped individual...shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance". (SECTION 504 - of the Rehabilitation Act of 1973, 29 U.S.C., 706 (S 84.4)

HISTORY

SECTION 504 is part of the Rehabilitation Act of 1973 (P.L. 93-112) and became law that year. At that time, Section 504 specifically applied only to discrimination in employment. In 1974, the Rehabilitation Act Amendments of 1974 (P.L. 93-516) extended coverage of Section 504 to all areas of civil rights including: education, post-secondary education, vocational training, employment, health, welfare, and other social service programs. (Preamble)

SECTION 504 RULES AND REGULATIONS went into effect April 28, 1977, when they were signed by HEW Secretary Joseph A. Califano, Jr. SECTION 504 applies to all recipients of HEW (Health, Education, and Welfare) funds, including:

- *States, Counties, Cities, Towns, Villages, and their political subdivisions*
- *Instrumentalities of states and their political subdivisions*
- *Public and Private Schools*
- *Public and Private Institutions*
- *Public and Private Colleges*
- *Public and Private Hospitals, clinics*
- *Other health service providers*
- *Public and Private agencies*
- *Other organizations and entitities receiving HEW funds*

(S 84.2)

DEFINITION: HANDICAPPED PERSON

"Any person who:

- *Has a physical or mental impairment which substantially limits one or more major life activities*
- *Has a record of such an impairment*
- *Is regarded as having such an impairment"*
- *Is a drug addict or an alcoholic*

(S 84.3)

DISCRIMINATION IS PROHIBITED IN:

- *Education of Handicapped Children*
- *Vocational Education Programs*
- *College Programs and Other Postsecondary Education Programs*
- *Employment*
- *Health, Welfare, and Other Social Service Programs*
- *Other Programs and Activities Funded by HEW*

ACCESSIBILITY

Service providers and employers are required to make "reasonable accommodation" to make programs, services and facilities accessible to the handicapped.

SECTION 504 and the EDUCATION of HANDICAPPED CHILDREN

The education provisions of SECTION 504 are closely coordinated with P.L. 94-142 (the Education for All Handicapped Children Act), signed into law November 29, 1975. Provisions of both P.L. 94-142 and the education provisions of SECTION 504 become effective September 1, 1978.

REQUIREMENTS:

All recipients of HEW funds which operate public elementary or secondary education programs must "provide a free appropriate public education to each qualified handicapped person who is in the recipient's jurisdiction, regardless of the nature or severity of the person's handicap". (S 84.33)

SECTION 504 PROHIBITS DISCRIMINATION BY:

- *Public and Private Pre-School Programs*
- *Public and Private Day Care Centers*
- *Public and Private Adult Education Programs*
- *Public and Private Elementary and Secondary Education Programs*

DEFINITION: APPROPRIATE EDUCATION and FREE EDUCATION

"the provision of an APPROPRIATE EDUCATION is the provision of regular or special education and related aids and services that (i) are designed to meet individual educational needs of handicapped persons as adequately as the needs of non-handicapped persons are met and (ii) are based upon adherence to procedures that satisfy the requirements of SS 84.43, 84.35, 84.36".
(S 84.33)

"the provision of a FREE EDUCATION is the provision of educational and related services without cost to the handicapped person or to his or her parents or guardian, except for those fees that are imposed on non-handicapped persons or their parents or guardians. ...if a recipient places a handicapped person in or refers such person to a program not operated by the recipient as its means of carrying out the requirements of this subpart, it may consist of payment for the costs of the program".

REQUIREMENTS:

- *Annual identification of handicapped children by public school districts*
- *Annual notification to parents of handicapped children's rights to special education services*
- *Implementation of an Individualized Education Program, in accordance with P.L. 94-142*
- *Pre-placement evaluation*
- *Evaluation procedures which "accurately reflect the student's aptitude or achievement level"*
- *Placement procedures which ensure proper documentation of information and which involve persons knowledgeable about the child in placement decisions*
- *Mainstreaming in educational programs and other activities*
- *Parent access to school records and confidentiality as to contents*
- *Periodic reevaluation of handicapped children*
- *Transportation to educational programs*
- *Procedural safeguards and Due Process Procedures which involve parents*
- *FREE RESIDENTIAL PLACEMENT (when such placement is necessary to meet educational needs of handicapped children)*
- *Equal opportunity for handicapped students to participate in:*
  - non-academic services - health services

- *extra-curricular activities*
- *recreational programs*
- *athletics*
- *counseling services*
- *special interest groups or clubs sponsored by the School*
- *transportation*
- *referrals to service providers*
- *referrals for employment purposes*

S 84.34 - 84.37

SECTION 504 and POST--SECONDARY EDUCATION

All post-secondary education programs and activities - including colleges and post-secondary vocational education programs and activities - are covered by SECTION 504.

REQUIREMENTS:

All recipients of HEW funds which operate colleges and other post-secondary education programs and activities are prohibited from discriminating against handicapped persons in:

- *Admissions*
- *Admissions tests (Admissions tests must be administered "so as best to ensure that ...the test results accurately reflect the applicant's aptitude or achievement level...")*
- *Pre-admission inquiries about applicant's handicap - except to implement policies of Affirmative Action*
- *Academic Programs*
- *Research Programs*
- *Course Examinations*
- *Occupational Training Programs*
- *Health Programs*
- *Counseling Programs*
- *Insurance Programs*
- *Financial Assistance Programs*
- *Physical Education Programs*
- *Athletic Programs*
- *Recreation Programs*
- *Transportation Programs*
- *Extracurricular Activities*
- *Student Employment and placement services*
- *Social and Fraternal Organizations which receive assistance from the recipient*
- *Housing*
- *Other Programs and Activities receiving federal funds*

(S 84.41-50)

ALSO PROHIBITED:

- *Rules that limit participation of handicapped students in educational program and/or activity*
- *Denial of auxiliary aids such as:*
  - *taped texts and tape recorders*
  - *guide dogs*
  - *interpreters*
  - *library readers*
  - *special classroom equipment for manually impaired*

(SS 84-43-50)

ACCESSIBILITY

All providers of education programs receiving H.E.W. funds are required to make "reasonable accommodation" to make programs, services, and facilities accessible to the handicapped.

SECTION 504 and EMPLOYMENT OF HANDICAPPED INDIVIDUALS

Discrimination in employment against qualified handicapped individuals is prohibited by SECTION 504, which states: "No qualified handicapped person shall, on the basis of handicap, be subjected to discrimination in employment under any program or activity to which this part applies". (S 84.11)

H.E.W. recipients - including programs receiving funds under P.L. 94-142 (Education for All Handicapped Children Act) are required to take Affirmative Action to employ and advance qualified handicapped persons.

DISCRIMINATION IS PROHIBITED IN:

- *Recruitment*
- *Advertising*
- *Processing of applications*
- *Hiring, termination, and rehiring*
- *Upgrading, promotion and demotion*
- *Tenure and seniority*
- *Transfer*
- *Fringe benefits*
- *Layoff & return from layoff*
- *Rate of pay or other compensation*
- *Job assignment and job classification*
- *Organizational structure and position description*
- *Line of progression*
- *Departure and return from leave of absence and sick leave*
- *Selection and financial support for training including:*
  - *apprenticeship*
  - *professional meetings*
  - *conferences*
  - *leave of absence to pursue training*
  - *other related activities*
- *Employer sponsored activities including:*
  - *social programs*
  - *recreational programs*
  - *other terms, conditions and privileges*

(S 84.11)

Employers are required to make "REASONABLE ACCOMMODATION to the known physical or mental limitations of a handicapped applicant or employee" unless they can demonstrate that this would impose an undue hardship. (S 84.12)

EMPLOYERS ARE REQUIRED TO:

- *Make facilities accessible to handicapped persons*
- *Acquire or modify or redesign equipment or devices*
- *Restructure jobs*
- *Provide part-time or modified work schedules*
- *Refrain from using tests or criteria which have disproportionate, adverse effect on employment opportunities of handicapped persons*

(S 84.12)

PENALTIES FOR NON-COMPLIANCE WITH SECTION 504 ARE:

"suspension or termination of or refusal to grant or to continue Federal Assistance or by any other means authorized by law". (S 80.8)

NON-COMPLIANCE COMPLAINTS SHOULD BE FILED:

- *In writing within 180 days*
- *To HEW Regional Civil Rights Office*

In Chicago: HEW REGIONAL CIVIL RIGHTS OFFICE
300 South Wacker Drive, 29th floor
Chicago, Illinois 60606
(312) 353-1781

APPENDIX

WHO WE ARE...WHAT WE DO...

The Coordinating Council for Handicapped Children is a coalition of more than 100 professional and parent organizations working together to actualize for the handicapped all the advantages that are freely granted to the non-handicapped, such as education, employment, housing, transportation, civil and social rights.

The Coordinating Council was organized in January 1969 by parents and professionals to obtain implementation of the State's Mandatory Special Education Act (HB 1407), and provide assistance to people of all ages on various problems of the handicapped.

CCHC was a pioneer as an "umbrella" agency that covered all handicaps and provided information and referral, advocacy, parent-training workshops, etc. .

CCHC'S MAIN ACTIVITIES INCLUDE:

1. Providing information to parents (and professionals) about the services for handicapped children to which they are entitled by law.

2. Providing ongoing training sessions in special education for parents and professionals.

3. Publication of fact sheets on Income Tax Deductions for parents, SSI (Supplemental Security Income) benefits, Special Education Law, PL 94-142, Section 504 of the Rehabilitation Act of 1973, and Careers information.

4. Publication of a monthly Newsletter which updates information on special education, mental health, new programs for the handicapped, coming events, new legislation, new equipment, special features such as "Help Line," "Swap Line," "Book Line," "Did you Know...?" and other items of special interest.

5. Organizing massive public information campaigns.

6. Answering requests for help for the handicapped.

7. Participation in "Speakouts," workshops, conferences, conventions, radio interviews, and television appearances.

8. Sending spokespersons to state and federal public hearings upon invitation.

9. This Directory of Services, the most comprehensive directory of services for the handicapped in the Chicago Metropolitan area.

10. Organizing parents of emotionally disturbed children to improve and increase day and residential services, through the Mental Health Coalition for Children.

CURRENT NEW PROJECTS INCLUDE:

1. A bookstore for parents and professionals, with publications of interest to both.

2. A public awareness project for public school children and their parents.

CCHC PROJECTS:

In addition to the regular ongoing activities, CCHC has worked on many important, specific projects:

1969-----Volunteer Mass Registration of Handicapped Children, including distribution of 60,000 flyers announcing a Child Hunt of handicapped children (one week project); 7 massive community meetings.

1969-71--Publication and dissemination/sale of more than 20,000 copies of Your Rights as Parents of a Handicapped Child.

1970-71--Publication and dissemination/sale of 5,000 copies of Your Guide to Services for Handicapped Children.

1972-----Joint Mass Child Hunt with Governor's Office of Human Resources---funded by federal and state monies (three month project).

1973-74--CCHC's Director Charlotte Des Jardins, was invited to Washington to work on an H.E.W. project, a 3-volume research book, Issues In the Classification of Children, which became the major impetus for mainstreaming provisions of federal and state legislation.

1974-----Public information and Parent-Helper Program---funded through the Chicago Community Trust (one year project).

1975-----Public Information Campaign under a contract with the Chicago Board of Education (three month project).

1975-----CCHC's Director served on HEW's Bureau of Education for the Handicapped Task Force to write Rules and Regulations for P.L. 94-142.

1976-----Public Information for Illinois White House Conference on the Handicapped---funded with federal money under special contract with the State of Illinois, Governor's Office of Manpower (four month project)

1976-79--PIC (Parent Information Center) referral and information service---under a renewable three year contract with HEW's Bureau of Education for the Handicapped.

SUMMARY

Throughout all the years of its existence, the Coordinating Council for Handicapped Children has promoted public information and awareness campaigns by utilizing its dedicated staff and volunteers who have, to date, answered more than 200,000 requests of help for the handicapped.

CCHC's publications, which are authoritatively used by professionals yet readily understood by laymen, are now sold on a world-wide basis, and extensively throughout the United States.

JOIN US, WE GET THINGS DONE

You can join the Coordinating Council for Handicapped Children, and receive an informative newsletter monthly, and other educational material regularly. Membership fees are:

IND./FAM. $10_____ CONTRIBUTOR $15_____ ORGANIZATION $30_____
LIFETIME $100 (IND./FAM. ONLY)_____ NEWSLETTER SUBSCRIPTION ONLY $8_____
Mail to:

Coordinating Council for Handicapped Children
407 South Dearborn, Room 680
Chicago, Illinois 60605

NATIONAL PARENT ORGANIZATIONS

AUTISM

National Society for Autistic Children
1234 Massachusetts Ave., N.W.
Albany, New York 12208

BLIND

American Council of the Blind
1211 Connecticut Avenue, N.W.
Washington, D.C. 20036

American Foundation for the Blind
15 West 16th Street
New York, New York 10011

National Association for Visually Handicapped
305 East 24th Street
New York, New York 10010

National Federation for the Blind
1346 Connecticut Avenue, N.W.
Dupont Circle Bldg., Suite 212
Washington, D.C. 20036

CEREBRAL PALSY

United Cerebral Palsy Association
66 East 34th Street
New York, New York 10016

DEAF

Alexander Graham Bell Association for the Deaf
3417 Volta Place, N.W.
Washington, D.C. 20007

National Association of the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910

DEAF-BLIND

National Association of the Deaf-Blind
2703 Forest Oak Circle
Norman, Okalhoma 73071

National Deaf-Blind Program
Bureau of Education for the Handicapped
Room 4046
Donohoe Building
400 6th Street, S.W.
Washington, D.C. 20202

EMOTIONALLY DISTURBED

Mental Health Association, National Headquarters
1800 North Kent Street
Arlington, Virginia 22209

EPILEPSY

Epilepsy Foundation of America
1828 L Street, N.W.
Washington, D.C. 20036

HEALTH IMPAIRMENTS

Allergy Foundation of America
801 Second Avenue
New York, New York 10017

American Cancer Society
777 Third Avenue
New York, New York 10017

American Heart Association
7320 Greenville Avenue
Dallas, TExas 75231

Cystic Fibrosis Foundation
3379 Peachtree Road, N.E.
Atlanta, Georgia 30326

HEALTH IMPAIRMENTS (Continued)

Juvenile Diabetes Foundation
23 East 26 Street
New York, New York 10010

National Hemophilia Foundation
25 West 39th Street
New York, New York 10018

National Kidney Foundation
Two Park Avenue
New York, New York 10016

National Tay-Sachs Foundation and
Allied Diseases Association
122 East 42nd Street
New York, New York 10017

LEARNING DISABILITIES

Association for Children with
Learning Disabilities
4156 Library Road
Pittsburgh, Pennsylvania 15234

MENTAL RETARDATION

National Association for Down's
Syndrome
P. O. Box 63
Oak Park, Illinois 60303

National Association for Retarded
Citizens
2709 Avenue E East
P. O. Box 6109
Arlington, Texas 76011

National Down's Syndrome Congress
528 Ashland Avenue
River Forest, Illinois 60305

PHYSICALLY HANDICAPPED

Arthritis Foundation
3400 Peachtree Road, N.E.
Atlanta, Georgia 30326

Muscular Dystrophy Association, Inc.
810 Seventh Avenue
New York, New York 10019

National Multiple Sclerosis Society
205 East 42nd Street
New York, New York 10017

National Paraplegia Foundation
333 North Michigan Avenue
Chicago, Illinois 60601

Spina Bifida Association of America
343 South Dearborn Street
Room 319
Chicago, Illinois 60604

SPEECH IMPAIRMENTS

American Speech and Hearing Association
10801 Rockville Pike
Rockville, Maryland 20852

ALL DISABILITIES

American Coalition for Citizens With
Disabilities
1346 Connecticut Ave., N.W. - Suite 1124
Washington, D.C. 20036

National Easter Seal Society for
Crippled Children and Adults
2023 W. Ogden Avenue
Chicago, Illinois 60612

National Foundation - March of Dimes
1275 Mamaroneck Avenue
White Plains, New York 10605

CLOSER LOOK
BOX 1492
WASHINGTON,D.C. 20013

OTHER IMPORTANT ORGANIZATIONS

BUREAU OF EDUCATION
FOR THE HANDICAPPED
U. S. OFFICE OF EDUCATION
DONAHOE BUILDING, ROOM 4921
400 - 6TH ST., SW
WASHINGTON, D. C. 20202
202/245-9405

U. S. OFFICE OF CIVIL RIGHTS
330 INDEPENDENCE AVENUE, SW
WASHINGTON, D. C. 20201
202/245-1821

COORDINATING COUNCIL FOR
HANDICAPPED CHILDREN
407 SOUTH DEARBORN , ROOM 680
CHICAGO, ILLINOIS 60605
312/939-3513

FEDERATION FOR CHILDREN WITH
SPECIAL NEEDS, INC.
120 BOYLSTON STREET,SUITE 338
BOSTON, MA. 02116
617/482-2915

NEW HAMPSHIRE COALITION FOR
HANDICAPPED CITIZENS, INC.
110 NORTH MAIN ST. - 3RD FLOOR
EAGLE CENTER
CONCORD, N H 03301
603/224-7005

TASK FORCE ON EDUCATION
FOR THE HANDICAPPED
812 E. JEFFERSON BOULEVARD
SOUTH BEND, INDIANA 46617
219/234-7101

SOUTHWESTERN OHIO COALITION FOR
HANDICAPPED CHILDREN
3024 BURNET AVENUE
CINCINNATI, OHIO 45219
513/861-2400

COUNCIL FOR EXCEPTIONAL
CHILDREN
1920 ASSOCIATION DRIVE
RESTON, VA. 22091
703/620-3660

CHILDREN'S DEFENSE FUND
1520 NEW HAMPSHIRE AVE., NW
WASHINGTON, D.C. 20036
202/483-1470

OTHER PUBLICATIONS OF THE COORDINATING COUNCIL FOR HANDICAPPED CHILDREN

1. DIRECTORY OF SERVICES FOR HANDICAPPED CHILDREN AND ADULTS

A spiral bound 311-page REDBOOK, listing 1,571 resources for the handicapped from birth through adulthood.

The REDBOOK, published by the Coordinating Council for Handicapped Children, lists 1,571 services in the Chicago Metropolitan area, both alphabetically and by disabilities, with easy to use charts of services for each disability group. Services listed include:

- 0-3 Programs
- Special Education Programs
- Vocational Education Programs
- Private Schools (Nationwide) Receiving State Funds
- Residential Facilities
- Sheltered Care Facilities
- Community Living Facilities
- Parent/Consumer Groups
- Homebound Services
- Hospitals and Clinics
- Diagnostic Facilities
- Individual and Group Treatment Services
- Camps and Other Summer Programs
- Information and Referral Services
- Rehabilitation Facilities

PRICE $10.00 PER COPY + $1.50 POSTAGE PER BOOK.

2. HOW TO ORGANIZE AN EFFECTIVE PARENT/ADVOCACY GROUP AND MOVE BUREAUCRACIES, a 130-page handbook which will show you:

- What Advocacy Is...What Advocacy Is Not
- How To Organize a Parent/Advocacy Group - Even Though You Never Organized Anything In Your Life
- How Parents Can Become Effective Advocates
- How To Tell An Advocacy Group From A Bureaucracy
- How To Tell a Bureaucrat From a Public Servant
- How To Get a State Charter and Tax Exempt Status
- How To Choose Effective Leaders
- How To Uncover Buried Talent
- How To Reach Out to Other Parents
- How To Make Your Parent/Advocacy Group an Action Group
- How to Move Bureaucracies
- How to Stay In Control and Keep Your Cool
- How To Decide When a Lawyer Is Necessary
- How To Lobby and Get Results
- How To Train Parents To Get Their Rights
- How To Make Headlines
- How To Make Effective Public Presentations
- How To Open An Appropriate Program In The Public Schools
- How To Open Your Own Private Program and Get Funding For It
- The Role of The Professional
- The Role of The Disabled Adult
- How To Recruit Volunteers
- How To Organize a Coalition
- How To Raise Money for Your Organization
- How To Keep Your Parent/Advocacy Group From Death's Door

PRICE $4.00 PER COPY + 50¢ POSTAGE PER BOOK.

PLEASE SEND ME:

_____ Copies of REDBOOK DIRECTORY OF SERVICES FOR HANDICAPPED CHILDREN AND ADULTS ($10 each + $1.50 postage per book)

_____ Copies of HOW TO ORGANIZE AN EFFECTIVE PARENT/ADVOCACY GROUP AND MOVE BUREAUCRACIES (at $4 each + 50¢ postage per book)

_____ Copies of HOW TO GET SERVICES BY BEING ASSERTIVE (at $4 each + 50¢ pstg)

20% discount available for orders of $100.00 or more in any combination

NAME _____ PHONE ( )_____

ADDRESS_____ CITY _____ STATE_____ZIP _____

RETURN TO: COORDINATING COUNCIL FOR HANDICAPPED CHILDREN
407 SOUTH DEARBORN STREET, ROOM 680
CHICAGO, ILLINOIS 60605